

## National Commission on Arthritis and Related Musculoskeletal Diseases

## April, 1976

## National Institutes of Health

**About the Cover Design:**

*According to a legend among the Pima Indians of the Southwest, the great warrior-leader Se-Eh-Ha once constructed a maze with winding, labyrinthine passages, as a refuge from his enemies.*

*That design, shown in the cover of this report, has been used for centuries by the Pima tribe. To them, it also represents a pattern of life, with all its obstacles and frustrations.*

*It may also illustrate the problem of arthritis — with all its obstacles and frustrations.*

Free, 1/2/78

United States

**National Commission on Arthritis and Related Musculoskeletal Diseases**

Arthritis: out of the maze,

## **Report to the Congress of the United States**

### **Volume IV, Part 2: Public Hearings**

**April, 1976**

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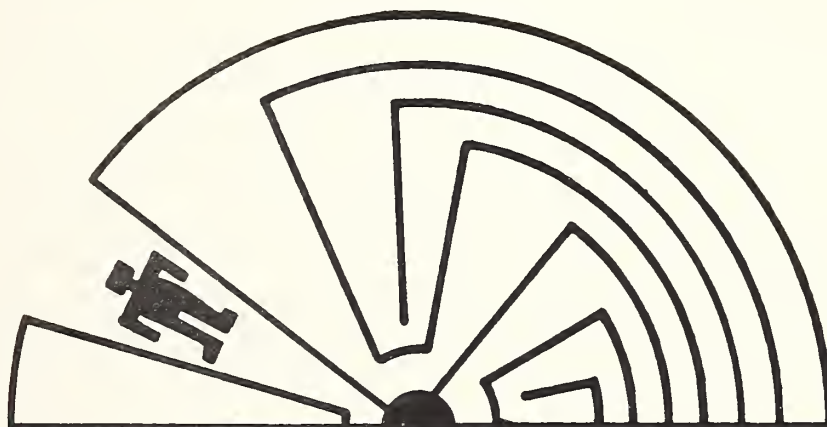
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**PENN-HARRIS MOTEL**  
**HARRISBURG, PENNSYLVANIA**  
**October 14, 1975**



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P R O C E E D I N G S

ENGLEMAN: The Commission solicits testimony which, hopefully, will be constructive and helpful to those of us who are charged with the responsibility of creating what is referred to in the Act as a National Arthritis Plan.

While we are interested in your present situation, we are much more concerned with your ideas--how they apply to improvement in the present situation.

The question is: How may the Arthritis Act provide this improvement, not only locally but nationally? What are your recommendations for implementation of a National Arthritis Act? How would you have them included in our report to Congress in the creation of this Arthritis Plan?

I will now ask the members of the Commission to introduce themselves. I am Eph Engleman, San Francisco, University of California.

POLLEY: Howard Polley, rheumatologist, Rochester, Minnesota.

SHARP: Gordon Sharp, rheumatologist, Columbia, Missouri.

LAWLESS: Oliver Lawless, rheumatologist.

FELTS: Bill Felts, rheumatologist, Washington, D.C.

GAY: William Gay, Associate Director at the National Institute of Allergy and Infectious Disease.

MELICH: Doris Melich, President of the Utah Chapter of the Arthritis Foundation.

ANTHROP: Mrs. Verna Anthrop. I have had arthritis for 15 years. I am just a citizen.

DONALDSON: Dr. William Donaldson, orthopedic surgeon, Pittsburgh.

BATCHELOR: Dr. Bill Batchelor, on the staff of the National Institute of Arthritis, Metabolism and Digestive Diseases, and the Executive Secretary of the Commission.

JENERICK: I am Howard Jenerick, Staff Assistant at the National Institute of General Medical Sciences, part of the National Institutes of Health.

SHIELDS: I am Marvin Shields, a physical therapist from Salt Lake City, Utah, representing the allied health professions.

LEWIS: I am Vivian Lewis, retired professor of kinesiology and physiology, Wilberforce, Ohio.

ENGLEMAN: Now, we will ask all persons appearing before the Commission to identify themselves, stating their full name, title, organizational affiliation and address.

We assume that you will have a written statement. This statement will be enclosed in a volume which will accompany our report to Congress.

Due to the number of persons who have requested appearance before the Commission, I must ask you to limit your testimony to five minutes. This will permit, hopefully, an additional few minutes for questions from the members of the Commission.

It is now my pleasure to introduce a former president of the American Rheumatism Association. Well, I should not be identifying you. You go ahead and do it yourself, Dr. Hollander.

TESTIMONY OF  
JOSEPH L. HOLLANDER, M.D.  
PROFESSOR OF MEDICINE, UNIVERSITY OF PENNSYLVANIA

HOLLANDER: Members of the Commission:

It is a privilege to be here. I come before you as a veteran of nearly 40 years of treating arthritis patients, teaching physicians in rheumatology, conducting research in this field, writing and editing papers and books on arthritis and organizing and conducting a large arthritis center.

I ask for nothing for myself as I have retired as administrator of my arthritis center and from doing research, but I am continuing in the fields of teaching and patient care, and in this capacity plead for increased support in several areas.

The cutback in support of research in arthritis-related conditions during the previous administration resulted in curtailment or an ending of worthwhile research, including our work with the controlled climate chamber in which we studied the effect of climate on arthritis.

I plead with you to urge that clinical research once more be supported, not just in a few cloistered, chosen centers of the elite, but in any institution that has the ideas, the equipment and the personnel to do the job.

Cutting off of training grants by NIAMDD has seriously jeopardized the production of experts in patient care for arthritis. At least two extra years of specialist training are now required to become a trained rheumatologist and a certified rheumatologist, and few can afford this without financial aid. To care for the millions of arthritic patients in the United States, we need many more experts. Before a physician can carry out research in this field, he needs adequate specialized training not now supported.

Special centers are needed to do research, for training arthritis specialists and for exemplary patient care, both medically and surgically, as well as for arthritis rehabilitation programs. I would plead that such centers be supported in numerous areas, not just in a very few places.

Several functions have been outlined in the National Arthritis Act which cannot be performed by a relatively few, elite arthritis centers. These public health aspects of rheumatology will vastly improve our delivery of good patient care through public education programs, family awareness programs, education of paramedical personnel, arthritis screening or case-finding programs in which I am particularly interested, and arthritis demonstration clinics for training of general or family physicians. These latter functions have been started by the Arthritis Foundation and furthered by regional medical program arthritis projects. You will hear from Dr. Tourtellotte later about these.

I plead also that funds for enlargement and continuation of such projects be made available. Thank you for your attention. I would be happy to answer questions if time permits.

ENGLEMAN: Thank you Dr. Hollander. Are there any questions from the members of the Commission?

LEWIS: What is your definition of a center?

HOLLANDER: A center is a place that is made up of a number of people collaborating to deal with research, with training and with patient care. I think unless it serves all three functions it cannot be truly called a center.

We have treatment centers, of course, in many hospitals where there may be two or three people, but a real center would involve research as well, and it would also involve training in these fields, rheumatologists, orthopedic surgeons in rheumatology or whatever.

ENGLEMAN: Any other questions? I gather that you, I am sorry, did you have a question?

ANTHROP: Yes, Dr. Engleman. Dr. Hollander, what would you include in your family awareness program?

HOLLANDER: We have made up one that we are administering this year, particularly as a model one to our regional medical program. This is for dealing with the patients themselves and particularly with their families to teach them how best to care for a patient with arthritis within their family group, in other words, avoidance of oversolicitous care, but proper comprehensive day-by-day care, such as home physical therapy and various other things involved in it. How to live with the person with arthritis is really our family awareness program in a nutshell.

ENGLEMAN: Thank you very much, Dr. Hollander.

VOICE: How do you actually carry on these programs? Do you have specific types of individuals that do the training in family relationships?

HOLLANDER: Well, many of us, as physicians, take part in this. Some of our paramedical personnel, for instance, are our physical therapists. One of these, who we call our arthritis rehabilitation instructor is very



active in this and acts as my right hand in this particular program. These people have been dealing with the problems for years and are, therefore, very helpful in getting our ideas across to the patients, to their families, and to their friends.

ENGLEMAN: Yes, Dr. Felts.

FELTS: Dr. Hollander, you are indicating that you believe the centers should come in, in part at least, as training sites for rheumatologists. As you are well aware, there is quite a lot of pressure nationally to develop more primary care physicians rather than specialists or subspecialists. Do you have any comment regarding how numbers of rheumatologists on a national basis might eventually get into the equilibrium of what is needed without excessive numbers?

HOLLANDER: We are trying very hard, Dr. Felts, to train our medical students to have a greater interest in this field. We are also trying to train all of our interns and residents to be better grounded in the fundamentals of rheumatology. We are doing this through our medical schools, and we are trying very hard to enlarge the number of medical schools in this country to give this training as a part of the core curriculum. At present, most of it is given purely as electives. Therefore, there are a good many students who go through and have no exposure to rheumatology at all.

Of course, as crusaders--that is all of us who have been in this field a long time really are--we try very hard to proselytize and steal the interest, if we can, of our students, of our house staff, and so on. We cannot expect to have all of the people who take care of arthritics to be trained rheumatologists. As you implied, it is impossible. But if we can broaden the base of knowledge, at least to the practical point of diagnosing and treating patients with arthritis, I think we will have accomplished our purpose.

I am hopeful that with many centers' support, such as that of the Arthritis Foundation, we can get more and more students interested; we can get more and more physicians interested; and we can train more and more general practitioners to have awareness in this field.

VOICE: Dr. Hollander, do you have an outreach program within your center? And what percentage of the peripheral communities do you get from the center?

HOLLANDER: I didn't get the original connotation. What kind of program?

VOICE: Well--

HOLLANDER: The training program, physicians--

VOICE: Outreach, yes.

HOLLANDER: Oh.



VOICE: The question really pertains to the centers which generally are in high-density population areas. The patient frequently is out peripherally. What percentage of the communities supply this sophisticated support that is city-based?

HOLLANDER: Well, in addition to our own personal lectures and appearances at various medical meetings in Allentown, Reading and all the area of our community or outreach program limits, we have, through our Greater Delaware Valley Regional Medical Program Arthritis Project, arthritis demonstration clinics in many small communities. In hospitals, we see the patients with the local doctors in attendance. You will hear about this later; I don't want to be redundant.

ENGLEMAN: I think we should go on. Thank you very much, Dr. Hollander. Dr. George Kunkel?

TESTIMONY OF  
GEORGE KUNKEL, M.D.  
MEDICAL DIRECTOR  
CENTRAL PENNSYLVANIA CHAPTER, ARTHRITIS FOUNDATION

KUNKEL: I am Dr. George Kunkel. I am a practicing rheumatologist in the Harrisburg area. I was the first to return with formal training in rheumatology some 7 years ago. I am on the staff of various local hospitals, and Medical Director of the local chapter of the Arthritis Foundation.

Dr. Hollander has already expressed in detail many of the things that I would say in general in terms of our local deficiencies. Specifically, I consider the deficiencies to lie essentially in three general areas. The first and perhaps the most important of these areas is the very keen need to improve the awareness and skills of diagnosis and management of the family practitioners and all the other medical professionals to whom the arthritis sufferers first present. Far too many times, in my experience, misdiagnosis or inadequate or inappropriate treatment results in needless suffering or significant deformity. These problems could be eliminated or reduced with the modalities already available. Additional inducements in the form of local and nonlocal medical seminars and or training courses to increase the recognition of the various types of arthritis, and basic medical management are needed at all levels of medical practice and education in this community region.

Secondly, we need to increase the public, and therefore the patient awareness, of the fact that there are many different types of arthritis and that something, sometimes a great deal can be done for all of these various types if the appropriate skills are available. Patients also need to know that we do have established arthritis clinics, and other rheumatologists besides myself in this area who can provide this instruction and service in cooperation with the individual's own private physician.

And, of course, the third area of need--and this is not just a local one, but is national and international, and Dr. Hollander has already

expressed this, is that more efforts are assuredly necessary to identify the causes of the different forms of musculoskeletal disease, and, of course, to find more effective measures to cure or to treat this collection of difficulties. Therefore, the support of research programs in the institutes of qualified investigators cannot and should not be abandoned, and certainly should be increased, if these diseases are ever to be controlled.

The similar need to support the training of additional medical and paramedical personnel in the fields of rheumatology should continue to be a major part of this effort to increase the overall benefits to the patient. This is a general statement of the deficiencies which I believe are national in scope, without any specific suggestions as to particular programs.

ENGLEMAN: Dr. Kunkel, do you have any personal bias as to the priorities? That is, you have given us a very nice statement as to where the needs exist. Are you willing to indicate which is the greatest need at this time?

KUNKEL: The greatest need at this time certainly is the area that I first mentioned, and that is increasing the awareness and the abilities of the family practitioners to whom the patients first present themselves. This is where the greatest immediate deficiency lies. The skills of many of our practitioners are not the equal of the individuals coming out of internal medicine and other residencies in the hospitals today.

ENGLEMAN: Dr. Batchelor?

BATCHELOR: May I ask Dr. Kunkel whether he would care to indicate how to go about this. Perhaps some start has been made. What do you see as the promising needs in getting this important job done?

KUNKEL: Well, we have had various programs with the attendance of local interns for the purposes of education and exposure. Various programs in this area have increased in the last few years. However, it seems that the majority of individuals who come to hear and learn seem to be the same physicians. The problem is how to reach those who do not want to or do not have the time or the interest. And I believe that this will require more field work clinics, the sort of programs that we do not now have set up in this region. Dr. Hollander referred to these clinics--where the family practitioner in outlying hospital participates with a consultant who has rheumatological training on the needs of a given patient.

ENGLEMAN: Any other questions? Thank you very much, Dr. Kunkel. Sophia Podgorski.

TESTIMONY OF  
SOPHIA PODGORSKI, R.N.  
DIRECTOR, NUTRITION SERVICES  
PENNSYLVANIA DEPARTMENT OF HEALTH

PODGORSKI: I am Sophia Podgorski, Director of Nutrition Services for the Pennsylvania Department of Health. I am the past president of the Pennsylvania Dietetic Association and also past president of the Association of State and Territorial Public Health Nutrition Directors.

In my opinion, there is a need for a strong, coordinated approach to nutrition research in relation to arthritis, to the development of the training opportunities for physicians and allied health personnel, such as dietitians and nutritionists as well as others in relation to the nutrition implications in the care of arthritics. There is a need for the collection and standardization of arthritis patient data, including data in regard to nutrition needs and the effects of nutrition modification in the total care of arthritic patients.

In reviewing some of the nutrition education materials for arthritic patients, I note that there is considerable emphasis on the fact that "there is no special arthritis diet" and on the importance of a well balanced nutritious diet. In my opinion, this is not enough.

The nutritional care of an arthritic patient should include a carefully detailed assessment and evaluation of the patient's nutritional needs, his or her attitudes and deepest concerns, and family history.

The importance of weight control, is, of course, obvious. However, much more care and attention is needed to help the patient attain desired goals, whether these goals are weight loss or, in some cases, the prevention of weight loss.

Although nutrition research in arthritis is scarce and fragmented, there appears to be evidence that suggests the need for diet modification in conjunction with the use of aspirin as well as other drugs as therapeutic agents to prevent or minimize its effect in causing gastric erosions and ulcerations and hemorrhage. Equally important is diet modification in the prevention or correction of iron deficiency anemia, which also occurs frequently among patients who take aspirin over long periods of time.

No less important is the need to consider the diet modifications necessary to insure optimum plasma ascorbic acid level and vitamin B-12 absorption, and a comprehensive diet approach to the total treatment of atherosclerosis, diabetes, the various hyperlipidemias and renal disorders which apparently share complex associations with arthritis and the treatment of its various forms.

In arthritic children, nutritional care must include consideration of nutritional needs for physical and mental growth and development, as well as previously mentioned factors.



In view of these important considerations in the treatment of arthritis, I strongly recommend a wider use of registered dieticians and nutritionists in the gathering of pertinent data in research projects and in nutrition and diet counseling at treatment centers.

Only by careful attention to the patient's needs, concerns and beliefs, and continuous support of the patient, can there be any hope of resisting the blandishments of food faddists fad diets and fad diet books which add so greatly to the already high financial burden of the arthritic patient.

I thank the members of the Commission for the opportunity to present this testimony today.

ENGLEMAN: Thank you Ms. Podgorski. Any questions? Yes, Dr. Polley.

POLLEY: I presume your services cover the whole state. About how many people are involved? Do you have anybody who is concentrating on arthritis, on the treatment, as such?

PODGORSKI: Actually, in the past few years our staff has been drastically reduced, and we have approximately 14 people for the entire State of Pennsylvania who are considered generalists in the area of nutrition and, on occasion, they are called in to work with arthritic patients.

My own experience with arthritis goes back to the period of my grandparents, when I saw them afflicted with arthritis. Later, my parents became similarly afflicted, and I now see this developing in my brother, my sister and myself.

ENGLEMAN: I am quite naive regarding this question, but do most states have this kind of service?

PODGORSKI: Yes, Doctor, they do. It varies greatly from state to state as to the number of people that they have in the specific areas.

ENGLEMAN: Thank you very much. Madeline Costello.

TESTIMONY OF  
MADALON COSTELLO  
EXECUTIVE DIRECTOR  
CENTRAL PENNSYLVANIA CHAPTER, ARTHRITIS FOUNDATION

COSTELLO: Thank you, Dr. Engleman. Ladies and gentlemen:

I am Madeline Costello, the Executive Director of the Central Pennsylvania Chapter of the Arthritis Foundation. I feel privileged to have been associated with the activities of the Arthritis Foundation for almost 20 years, both as a volunteer and as a paid executive director. This chapter's 23 county area serves a population of 2,235,188 of which an estimated 223,518 are victims of some form of arthritis.

Our fundraising efforts have progressively increased. Thirty-five percent of the monies go to national research, but it is not enough. It is mandatory that sufficient Federal funding be appropriated to assist the Arthritis Foundation in developing stronger research programs.

The current situation in one-third of the nation's medical schools is deplorable. A properly accredited medical school should be required to have a department of rheumatology with more hours of teaching in this field available to the students. You understand this is a layperson speaking. We are fortunate to have a competent medical school in our area, the Pennsylvania State University, M. S. Hershey Medical Center.

During each of the past 5 years the chapter has been providing a visiting professorship in rheumatology to the Medical Center. Presently, the professorships are of 1-year duration, but we are hopeful that our preliminary efforts may ultimately develop into a full-fledged department of rheumatology.

Although the fact that 1 out of every 10 persons is believed to be afflicted with arthritis, and 1 out of every 5 families is said to be affected, the medical schools appear to be very reticent about establishing such a department, although the incidence of the disease is greater than that of any other disease.

There are three arthritis chapters in the Commonwealth of Pennsylvania. We have initiated steps toward the formation of a state task force on arthritis. As of this writing, this had not been accomplished. I could be pleasantly surprised.

The writer and members of this chapter feel that consideration of sufficiently appropriated funds channeled through state health departments and local Arthritis Foundation chapters could materially assist in achieving screening, detection and control programs and standardization of arthritis patient data to facilitate the collaborative clinical research program for improving arthritis patient care.

This chapter has recently been awarded a grant to implement a much needed patient-family education program. It is hoped that consideration will be given furtherance of the RMP's or a similar vehicle for the continuance of such programs. This Chapter can boast of only 10 members of the American Rheumatism Association in this area. One is an orthopedist; the others are limited to 5 counties of the 23. Similarly, there is a great lack of clinical facilities. These are available in only 4 of the 23 counties. Thank you.

ENGLEMAN: Thank you, Ms. Costello. Any questions? I thought I heard you make the comment that you hope that the funding which might come out of this Arthritis Act could be used to assist the Arthritis Foundation. Would you just elaborate on what you mean by that?

COSTELLO: The thinking was, Dr. Engleman, that perhaps through state health departments working cooperatively with the local chapters, this collective concentration on the problem might accomplish something in the areas that are in such great need.



ENGLEMAN: Do you have such an arrangement in this state now?

COSTELLO: Unfortunately, we don't.

ENGLEMAN: Yes, Dr. Polley.

POLLEY: Why do you think there is such a shortage of rheumatologists in this area, I mean in the medical schools?

COSTELLO: Well, there is definitely a shortage of rheumatologists in the area, Doctor, I think perhaps because we are out in the boondocks, so to speak. We are not near the medical schools. It seems that most of the rheumatologists are concentrated in the larger cities. Perhaps someone else would have a better answer for that.

ENGLEMAN: Yes.

SHARP: I would like to follow up your comment about trying to get a rheumatology unit at the medical school where one does not now exist. Could you elaborate a little more on what you see as the nature of the difficulties preventing that from happening?

COSTELLO: I guess, just off the top of my head, it is my understanding that this is not given a very high priority.

SHARP: So you feel it is a slowness of the university system to respond to this as an important need?

COSTELLO: Yes.

SHARP: Let me ask you one other question, too, if I may. You talked about a patient-family education program, and this was funded through an RMP grant, was it?

COSTELLO: Yes.

SHARP: Could you give me some idea of how those grant monies were utilized? What were the aspects of the program that required that kind of support? And, secondly, could that have been done with community support, without any RMP support?

COSTELLO: You will be hearing from our administrator of this project about implementing the patient-family education program, which I think will give you a better explanation.

SHARP: But there was some funding by the RMP?

COSTELLO: Yes.

SHARP: Since there are so many important things that will need to be funded under the Arthritis Act, I was wondering whether you feel that any part of this program might have been carried out even if that RMP grant had not come across?

COSTELLO: Well, it seems that on the small scale on which we were able to do it, Doctor, it wasn't too effective. We needed the manpower, the necessary manpower to effect this.

ENGLEMAN: Yes, Dr. Felts.

FELTS: Ms. Costello, I know that you represent the Central Pennsylvania Chapter. I wonder, though, again following up on Dr. Sharp's questioning slightly, if you would perhaps tell us how many medical schools there are in the State of Pennsylvania and how many of them do have divisions of rheumatology? Do you happen to know that?

COSTELLO: I am afraid you have me there, Dr. Felts.

ENGLEMAN: Dr. Hollander might be able to answer that question. Can you Doctor?

HOLLANDER: There are five in Philadelphia, one in Hershey, and one in Pittsburgh, but only the five in Philadelphia and the one in Pittsburgh have rheumatology centers.

FELTS: Thank you.

ENGLEMAN: Thank you very much, Ms. Costello. I think we should now go on to Jan Nicholson.

TESTIMONY OF  
JANICE NICHOLSON, P.T.  
PROJECT ADMINISTRATOR  
REGIONAL ARTHRITIS SERVICES PROJECT, ARTHRITIS FOUNDATION

NICHOLSON: I am Janice Nicholson, physical therapist and Project Administrator of the Regional Arthritis Services Project under the Arthritis Foundation which is sponsored by an RMP grant.

Since becoming Project Administrator of the Regional Arthritis Services Project in central Pennsylvania, my awareness has become intensified for the need of quality, comprehensive management to patients with rheumatic diseases. The project is attempting to address itself to the needs which exist in our region in the area of:

- (1) Increased dissemination of quality instructional procedures and techniques for effective patient-family education.
- (2) Broadened educational programs for professionals and paraprofessionals to ameliorate the delivery of care in the area of rheumatic diseases.
- (3) The development of a regional clinic for accessibility and comprehensive management to patients with arthritis.

Central Pennsylvania consists of 23 counties with approximately 16,371 square miles, and a combined population of more than 2.2 million. It is

known that 1 of every 10 individuals has some form of arthritis, and it can therefore be extrapolated that in central Pennsylvania alone there are nearly 225,000 individuals suffering from arthritis.

Central Pennsylvania currently has five established outpatient clinics in four counties which are staffed by paid rheumatologists, and which offer services to the adult population afflicted with rheumatic disease. The five facilities were queried as to the total number of patients. This was tabulated on a regional and yearly basis. The annual visitation total varied between clinics from 106 patient visitations to 5,200. The summation of the 5 facilities was approximately 7,200 annual visits, two-thirds of which were patients involved in follow-up care.

In addition to the five clinical facilities, there are four rheumatologists in central Pennsylvania who offer services through private practice. A query was again made in reference to the total number of patient visitations, and the data collected revealed that 8,344 annual visitations are being made to private practitioners specializing in rheumatology. Again, approximately two-thirds of these services are being rendered to patients under previous care.

With the increase in consumer consciousness has come the need for increased patient-family education. However, a review of the educational instructions rendered to the patient by professionals or paraprofessionals reveals a dearth of quality instructional procedures, techniques and materials. Of the five clinics and four private practices offering services in central Pennsylvania, only two utilize didactic group instruction and provide written literature. The current mode of patient-family education has been informal verbal instruction primarily on a one-to-one basis with occasional demonstration as to technique and procedure. Without the development of curricula this instruction becomes piecemeal and therefore ineffective.

I am requesting that the Commission give consideration to these needs and to the funding which is essential to alleviate these deficits. With all nine facilities being located in only four counties of central Pennsylvania, an extreme void is being produced in the majority of our rural regions. It is suggested that with the providing of educational programs for professionals and paraprofessionals will come an increase in expertise in delivery of quality patient care. This quality care will manifest itself not only in the area of disease management and treatment, but also an improvement in instructional procedures and techniques for sophisticated patient educational programs. To increase the dissemination of instruction and ultimately the quality of programs, serious consideration needs to be given to the development of additional clinics. Accessibility of services is imperative for the comprehensive approach necessary to manage the complexity of problems encountered with rheumatic diseases. Thank you.

ENGLEMAN: Thank you Ms. Nicholson. Any questions? Yes.

LEWIS: To what extent are minority ethnic groups involved in your projects?



NICHOLSON: In reference to?

LEWIS: Any project.

NICHOLSON: As staff or as recipients of the services?

LEWIS: Staff, recipients, consumer of the services.

NICHOLSON: At the moment there are four staff members on the project, none of which are minorities. Minority groups will be recipients, though, of services offered, and will be offered to any patient and family involved with rheumatic diseases, if that is an adequate answer to your question. I am not sure I quite understood. Did you mean in reference to services being rendered?

LEWIS: I meant both, those who are administering the services and those who are recipients of the services.

NICHOLSON: Minorities will be recipients of it. The staff of the project itself is small and only consists of four.

ENGLEMAN: Yes.

LAWLESS: Ms. Nicholson, just a question in relation to the numbers you quoted. I think a total of 18 or 15,000 patients were seen. Do you have any breakdown as to what percentage were first-time arthritic presentations to these services versus what happens to them? Are they referred back to primary care physicians or do the rheumatologists become the primary care physicians?

NICHOLSON: I do not have a breakdown as to the total number. These were patient visitations, not patients themselves. Approximately one-third of that number were new patients. In reference to who delivered follow-up care, it was a combination of both the primary physician and the rheumatologist working in conjunction with one another.

SHIELDS: One of the things that was alluded to was the fact that a potential way to have all doctors trained in rheumatology is to have more rheumatology departments in medical schools. It is obviously not possible for two or three allied health people to treat all the people with arthritis. How do you see allied health people receiving the kind of training they need to better treat patients with arthritis?

NICHOLSON: I voted for this in my testimony. And I think this one comes back to the developing of educational programs. Presently, they are few and far between in central Pennsylvania for both the professional and the paraprofessionals. We have many more paraprofessionals than we do professionals in central Pennsylvania. As you say, they will be seeing the majority of the patients.

There is a need for not only more programs, but accessibility to these programs. Most of these programs are being offered in the larger cities and counties within central Pennsylvania. The project is attempting to take these educational programs out to the paraprofessionals who, up until

this time, have not had the opportunity to attend continuing educational programs.

Many of these paraprofessionals are the only professionals within their hospitals--maybe just one PT--and, up until this time, could not take two or three days off to come to the Harrisburg area or to the Philadelphia area for these inservices, so the project would like to take the programs out to them.

SHIELDS: So you can see it mainly as training physical therapists after they have graduated from physical therapy school in their specialities in arthritis, or would you see more done at the basic level when they were in training.

NICHOLSON: Yes, I prefer to see it done while they are getting their training in the schools and universities themselves.

ENGLEMAN: Yes.

LAWLESS: Can I just follow up on that point? Did you say that there were more paraprofessional people in this area than professionals?

NICHOLSON: Right, because right now there are only seven rheumatologists in central Pennsylvania.

LAWLESS: In your experience, what integration-coordination exists between the private practitioner, the primary care physician, and the paraprofessional in relation to patient care or is the contact directly to rheumatologists?

NICHOLSON: Up until this time, it has been primarily back to the rheumatologist. Unless the primary care physician is going to the hospital or the clinic where the patient is being seen, there is very little written correspondence or telephone correspondence back to the paraprofessionals, and unless, of course, the primary physician is at the facility when the patient is being seen either as an inpatient or an outpatient.

ENGLEMAN: Time doesn't permit a detailed answer to this question, so you may answer it yes or no. Do you have an ongoing system of evaluation of what you are doing?

NICHOLSON: Yes.

ENGLEMAN: Will you be sure to include it in your written testimony?

NICHOLSON: The project is only one-month old and--

ENGLEMAN: Oh, but you do--you have an ongoing prospective mechanism by which you can assess what you are doing?

NICHOLSON: An evaluative tool is being developed prior to the services and programs being developed.



ENGLEMAN: Will you include whatever you can in your written testimony?

NICHOLSON: Yes.

ENGLEMAN: Thank you very much.

NICHOLSON: Thank you.

ENGLEMAN: Marx Leopold?

LEOPOLD: I have my own statement, and I have been furnished a statement by a patient from the central Pennsylvania area who can't be here today because he is in the hospital. And I would like to present my statement and answer any questions that you may have, and then this statement is a relatively short one.

ENGLEMAN: How much time is this going to take?

LEOPOLD: Well, my statement only takes three or four minutes, and this will take less than a minute.

ENGLEMAN: Would you identify yourself, please.

LEOPOLD: Yes.

TESTIMONY OF  
MARX LEOPOLD  
PRESIDENT, CENTRAL PENNSYLVANIA CHAPTER  
ARTHRITIS FOUNDATION

LEOPOLD: I am Marx Leopold. I am the President of the Central Pennsylvania Chapter of the Arthritis Foundation. I am a lawyer by training, and formerly was the general counsel of the Pennsylvania Department of Public Welfare. Currently, I serve as a consultant to the Pennsylvania legislative committees concerned with health and welfare issues. On behalf of the Central Pennsylvania Chapter of the Arthritis Foundation, I want to give you an official welcome to the Harrisburg area.

My remarks, however, should not be considered to be the official position of any of those committees or of any individual legislator, nor should they be considered the official position of the arthritis chapter with which I am affiliated.

We feel honored yet somewhat perplexed by your choice of Harrisburg for one of your national hearings. Honored because I know you are going to only a few areas, but perplexed because, although there is a great reservoir of concern and interest by the people of central Pennsylvania, there is little concern shown by the entities that could help if they indicated a modicum of interest. I refer specifically to the Hershey Medical School and the decisionmakers responsible for the chronic disease activities of state government.

Hershey Medical School, which holds itself out as a medical school catering to the needs of the family physician, does not have a rheumatologist on its staff, and does not, so I am told, train students to deal with rheumatic disorders.

Within the Department of Health there is a Bureau of Adult Preventative Health Programs with a Division of Chronic Diseases. Yet the budget presentation to the General Assembly for the current fiscal year for that department, bureau and division contains no reference to arthritis or rheumatic disease.

Unfortunately, Pennsylvania is not unique. States do little concerning arthritis, and medical schools generally ignore the problem.

Millions of work days are lost in this country due to restricted activity, bed disability or occasional sick days because of arthritis. In addition to disability benefits paid by the Social Security Administration the country is paying the expense for medical care for arthritis sufferers, yet the National Arthritis Act provides little in terms of monetary incentives to states or medical schools.

As much as I dislike saying it, it is undeniable that money establishes priority in health care. We may not be able to change the system of priority setting, but we can work within that system by providing appropriate funds for health services to arthritics, administered by the states, and by providing funds as incentives to medical schools to teach about a condition that directly affects 20 million Americans.

If the country were willing to annually spend \$100 per person directly affected by arthritis and related diseases for the purpose of research grants to the states for services and incentives to medical schools to produce practitioners knowledgeable in the field of arthritis, there would be a \$2 billion fund which might make the National Arthritis Act really meaningful.

Inasmuch as the cost of lost work productivity due to arthritis alone or the cost of direct medical care to arthritics alone more than likely exceeds the cost of such a program, this would be money well spent and for which the country would ultimately secure a return.

I know you are directed by the law to establish a long-range arthritis plan. However, without sufficient funds your plan will be meaningless.

Thank you for giving me the opportunity to present my personal views this morning.

LEOPOLD: This is a statement of a person who has been a patient for many, many years, who has been active as a helper to the Arthritis Foundation in the central Pennsylvania area. His name is Norman Strawser.

TESTIMONY OF  
NORMAN STRAWSER  
PATIENT-LAYPERSON  
PRESENTED BY MARX LEOPOLD

"Honored guests, ladies and gentlemen, and to the most dedicated and gracious lady I know, Madalon Costello:

"I would like to tell you what arthritis means to me: constant pain 24 hours a day; inability to participate in family activities, sports, travel, etc.; curtailing all activities; yearly trips to the hospital; erosion of life savings; early forced retirement with little or no income; the loss of many friends; and the end of my music career.

"What the Arthritis Foundation means to me: In 1964, the late Robert Cook diagnosed my illness as rheumatoid arthritis, informing me that it doesn't kill you, it just makes you wish you were dead.

"Through Foundation money, Dr. Cook asked if I would like to be a volunteer for drug studies. My first drug study, I am happy to say, was a drug called Indocin, which is now helping millions of patients, but this takes millions of dollars.

"I continued on drug studies for the next 5 years, many of which failed, but the studies still cost millions of dollars.

"At this point, I am more concerned about the very young than for myself. When you see an 18-month-old child suffering from a disease with no known cure, then I think the government should appropriate funds for the research of arthritis the same as they do for other diseases.

"Ladies and gentlemen, in all the past 11 years every type of assistance that I required was freely given with no questions asked or the amount of money involved mentioned. I am most grateful for this.

"It is with regret that I am unable to be present at this hearing. But once again I am a patient at the Harrisburg Polyclinic Hospital involved in a new technique of surgery. I am encased in a body cast attached to a halo with four screws embedded in my skull. Without the help of my chief physician, the Lord, Jesus Christ, I know I would not have made it.

"If our government would allocate funds for the research of arthritis, it could prevent our young children from having to endure this type of surgical procedure."

ENGLEMAN: Thank you.

LEOPOLD: Thank you on behalf of Mr. Strawser and myself.

ENGLEMAN: Any questions from the members of the Commission? I think some of the questions you raised may be answered by our next witness, Dr. Pfeiffer.



SUBMITTED STATEMENT OF  
MILDRED PFEIFFER, M.D.  
DIRECTOR, DIVISION OF CHRONIC DISEASES  
PENNSYLVANIA DEPARTMENT OF HEALTH

I am licensed to practice medicine in Pennsylvania, have a master's degree in public health, and am board certified in internal medicine. I am a member of the American Rheumatism Association, a recipient of a Distinguished Service Award from the National Arthritis Foundation and a Governing Board Member, having also served previously as a member of the Community Service Committee and Paramedical Professional Committee. I am a charter member of the Central Pennsylvania Chapter of the Arthritis Foundation, former president, and continue to serve on the Board of Directors and Medical and Scientific Committee (former chairperson). I also served as the first chairperson of a Pennsylvania Arthritis Coordinating Committee. After engaging in private practice, research and teaching (e.g., Clinical Associate Professor of Medicine, Woman's Medical College of Pennsylvania, currently Pennsylvania Medical College, I was asked, in 1952, to set up a new Bureau of Chronic Diseases for the Pennsylvania Department of Health when that department became reorganized professionally. Since then I have set up planning and other units and have returned to the Division of Chronic Diseases. During this period of time, arthritis has been one of my concerns because so little public and private support was given to this common, painful collection of joint, collagen, connective tissues and supporting structure diseases that are painful, crippling, and costly but do not appear high in "causes of death", like cancer, heart disease and accidents.

This is not intended to be a personal recital but is meant to support a point of view as to some needs in the arthritis field today, exclusive of specific basic research areas.

I. As one of the national alerters to assist in the passage of the National Arthritis Act, it was gratifying to know that arthritis had become an official part of the National Institutes of Health. As broad in concept as the Act is, from the standpoint of community health and the consumer-patient-family, there needs to be more specific recognition of state (and local) health departments. National health insurance is not yet here and comprehensive health planning, review organizations, RMO's, primary care centers, and enough specialized rheumatic disease centers are still in the stage of development. The voluntary arthritis agencies are doing noteworthy and useful work, but a few million dollars so raised will not take care of the needs of arthritics or arthritics to be, or the education of those providing services.

II. Because arthritis was not generally looked upon as a public health problem in the fifties, I supported the creation of the voluntary arm of public health, the Central Pennsylvania Chapter of the Arthritis Foundation, in order to obtain resources for doing something in the arthritis field (a little less complicated then, since chemotherapy, immunotherapy, enzymes, hormones, surgery, and improved diagnostic techniques were not so advanced and the related collagenous or connective tissue diseases and more subtle systemic diseases related to arthritis, were not generally included in the subspecialty of rheumatic diseases).



In serving as its volunteer Medical Director, it was possible to plan and initiate programs that could be implemented by the Chapter in cooperation with various units in the Pennsylvania Department of Health, the Medical Societies, the National Institutes of Health, the National Foundation, and the other Arthritis Chapters, Dietetic Association, Health Councils, Bureau of Rehabilitation, Nursing Associations, physiotherapists, social workers, etc. The Chapter itself benefited by the wider contact with the public and special groups in its growth so that now it is carrying the ball and has received an RMP grant on its own. Thus was executed the following:

- Two Governor's Conferences on Arthritis
- A Rheumatic Disease in Industry Seminar
- An educational seminar for nurses, physical therapists, social workers, occupational therapists (with an NIH grant)
- a series of nutrition and arthritis seminars held throughout the State on a regional basis
- The creation of an Arthritis Coordinating Committee which brought together the then Pennsylvania chapter and representatives of the State Medical Society, State Department of Health, others.

A grant from the State Health Department, Division of Chronic Diseases, was made to Dr. Ehrlich, Einstein Medical Center, Philadelphia, for a demonstration, multidisciplinary clinic for the diagnosis, treatment, and rehabilitation of the arthritic patients. This involved social work, nursing, educational and vocational counseling, rehabilitation and home care. It was very successful but had to be terminated because of austerity needs. It served to coordinate the thinking and objectives of the various agencies represented by the Pennsylvania Arthritis Coordinating Committee.

Educational materials were prepared or bought and distributed in cooperation with the Arthritis Foundation and the health department. The publications, such as Strike Back at Arthritis prepared by the Public Health Service, were purchased and distributed in connection with home and family care, patient education, as well as to professionals.

I and II, then, lay the groundwork for further remarks.

The prevalence, incidence, costs, distribution, lack of rheumatologists and centers and relative scarcity of funds for research are well known to the Commission, since the National Foundation has done so well in publishing these national data. Therefore, I will not repeat them. Instead, I should like to briefly refer to some of the activities in Pennsylvania connected with arthritis at the present time.

The Regional Medical Programs, of uncertain futures, have awarded grants to the Philadelphia area (project directed from Hahnemann Medical Center), St. Margaret Hospital, Pittsburgh, and to the Central Pennsylvania Arthritis Chapter. These have been, or are being, used to

counsel and educate arthritis patients and their families in how to carry out their physician's plans, and to teach self-help. Outreach programs have been set up to teach other physicians, both family or primary, and other specialists, the fundamentals of diagnosis and modern treatment, by a team faculty (rheumatologists, surgeons, radiologists, interns, etc.) going once a week or, at most, once a month, to community hospitals in order to evaluate patients, suggest treatment and to observe results. This is a continuing education program and will help to set up rheumatology clinics or services in hospitals not now having them. It should also be useful in future PSRO relationship.

Also, many different types of seminars have been set up for nurses and allied personnel as well as physicians in treatment and rehabilitation. The whole field of rehabilitation is emphasized. The medical schools are cooperating. The State Health Department has helped to support some evaluation and rehabilitation at a mid-state community (Williamsport), but has not had the staff nor funds for an expanded program. The Governor has shown interest in naming a state task force on arthritis and the three chapters have cooperated in suggesting possible members, and to focus on the top priority needs in various parts of the state. Research, of course, has had some support at the universities, but this has come mainly from the National Foundation or a branch of HEW. No registry of patients exists, but a grant for this had been applied for some years previous. A 1-week lectureship in arthritis by an outstanding rheumatologist for Hershey Medical Center, and hospitals in Danville, York, Lancaster, Harrisburg and Hershey has been funded by the Central Pennsylvania Arthritis Foundation from independently obtained funds but no rheumatology clinical unit has been established there.

On the basis of the above, I should like to enumerate without detail the needs as perceived from my vantage point up to the present time (excluding specific laboratory or clinical research).

- (1) Provision of funds directly to state health departments for staff, state and local programs, as evaluated by the department, and for greater coordination and/or awareness of activities in the arthritis field.
- (2) Assistance in supplying a full range of rehabilitation seminars to all patients and as early after diagnosis as possible. This includes children and adults of all ages.
- (3) Training for more personnel and existing personnel in teaching patients and families and providing the physical and occupational therapy and home care needed, especially for nurses, skilled home health aides, etc.
- (4) Support of outreach teaching programs from medical teaching centers to community hospitals, HMO's, neighborhood health centers, community nursing associations, etc., in order to develop rheumatology expertise and interest in physicians.

- (5) Develop statewide coordinating committees in order to facilitate the flow of information as to needs, projects, and plans. Staff time is important to keep such a group useful.
- (6) Assist in the development of rheumatology services and teaching in all medical (including osteopathic) schools, including the new Pennsylvania State University Medical School at Hershey.
- (7) Subsidize fellowships in rheumatology for physicians so that more will concentrate on getting, using and sharing new knowledge or applying more broadly their present knowledge.
- (8) Continue to investigate ways to find arthritis that is asymptomatic or of finding individuals who have some form of arthritis but have not been included in the mainstream of what can really be done today to help them. Counseling and follow-up are important.
- (9) Widespread use of media and other informational channels, including public forums, to include the awareness of the public regarding self-help, recognition of personal or family needs, the meaning of the treatment can help to obtain definitive help. Volunteers can also help here.
- (10) Convening of leaders in insurance, industry, agriculture, labor and rehabilitation to provide more coverage for arthritics, job training and placement, home and at work support.
- (11) Communication with public providers (Medicare, Medicaid, VA, potential national health insurance representatives, EMO's, PSRO's comprehensive health planning agencies, hospitals, medical societies, etc., so that the broad needs, over a considerable length of time, and involving the cost of diagnosis, continued treatment and follow-up are given attention via the hospital bed, outpatient department, health center, occupation-connected medical department, schools, transportation means, home care, and underwriting of costs are all included in community or regional planning and implementation (not all can afford \$200 for just one muscle biopsy alone).
- (12) Develop consumer advocates to assist the patient and family, and to listen to him, in recognizing self-needs and sources of help, and in bringing to the attention of elected representatives the need for public, social, political and economical concern for this leading group of costly disorders.
- (13) Support the development of special centers equipped to study the newer intersystem relationships of disease and wellbeing, as exemplified by chemotherapy, immunotherapy, etc., as well as specific mechanical-electrical aids and surgery.
- (14) Encourage group projects utilizing the voluntary arthritis groups and those associated with public health and preventive medicine.



- (15) Emphasize to preventive medicine, community medicine, or public health departments, and public health schools, that chronic disability need not be complete, needs specified attention in quantity and quality, may be prevented or arrested, and the quality of life improved for over 50 million residents of the U.S.A.
- (16) Use of "carrot" or "club" psychological approach to state and local departments of health so that they give rheumatic and allied diseases a higher priority. Money seems to be the answer and is proven by the public still supporting emotionally the diseased or injuries which affect them, e.g., cancer, heart disease, lupus erythematosus, epilepsy, Huntington's Chorea, multiple sclerosis, hemophilia, blindness, diabetes, Tay-Sachs disease, sickle cell anemia, Women Against Rape, Women's Lib, etc. The categorical approach is still with us and has consumer meaning in spite of comprehensive, esoteric, objective planning and primary care notwithstanding.
- (17) Encourage PSRO, utilization review groups, health service area councils, hospital and nursing home licensure agencies to include specific standards and evaluation of how rheumatic disorders are cared for in continuum on a community basis, and not just within the walls of one facility.
- (18) As is encouraged in the National Cancer Social and Rehabilitation Plan covering 17 comprehensive cancer centers in the U.S.A., assist in setting up WATS lines or other mechanisms for providing accurate, fast information to patients or other public as to the value of certain remedies, safety and accuracy of tests, referral to adequate quality sources of diagnosis, treatment, rehabilitation, and sources of assistance for social, emotional and financial problems related to the rheumatic diseases. With time, comprehensive, on-line information centers, with proper training of personnel, could be set up for many chronic illnesses as part of public health education, continued education and self-help toward personal health maintenance.

## TESTIMONY OF MILDRED PFEIFFER, M. D.

PFEIFFER: Members of the Commission:

It is a privilege for me to be here and to try to present the needs of our regions as I perceive them.

I am a physician, and I am currently the Director of Chronic Diseases at the State Health Department, but I have also been very active and involved in the Central Pennsylvania Chapter of the Arthritis Foundation. I have tried to work with them all these years, but, unfortunately, as has been already stated, we have had very little in the way of specific budgetary or state support in our own department.

The needs and recommendations, as I see them, are:



- (1) Provision of funds directly to state health departments for staff, state and local programs as evaluated by the department, and for greater coordination and or awareness activities in the arthritis field.
- (2) Assistance in supplying a full range of rehabilitation seminars to all patients, and as early after diagnosis as possible. This includes children and adults of all ages.
- (3) Training for more personnel and assistant personnel in teaching the patients and families and providing the physical and occupational therapy and health care needed, especially for nurses, skilled home health aides, and so on.
- (4) Support of outreach teaching programs for medical teaching centers, for community hospitals, HMO's, neighborhood health centers, community nursing associations, and so on, in order to develop rheumatology expertise and interest in physicians.
- (5) Develop statewide coordinating committees in order to facilitate the flow of information as to needs, projects and plans. Staff time is important to keep such a group useful.
- (6) Assist in the development of rheumatology services in teaching in all medical (including osteopathic) schools, and including the new Pennsylvania State University Medical School at Hershey.
- (7) Subsidize fellowships in rheumatology for physicians so that more will concentrate on getting, using and sharing new knowledge or applying more broadly their present knowledge.
- (8) Continue to investigate ways to find arthritis that is asymptomatic or of finding individuals who have some form of arthritis but have not been included in the mainstream. A lot can really be done today to help them. Counseling and follow-up are important.
- (9) Widespread use of media and other information channels, including public forums, to improve the awareness of the public regarding self-help, recognition of personal or family needs, the meaning of the treatment, and help to obtain definitive care. Volunteers also can help here.
- (10) Convening of leaders in insurance, industry, agriculture, labor and rehabilitation to provide more coverage for arthritics, job training and placement, home and at work support.
- (11) Communication with public providers, Medicare-Medicaid, VA, potential national health insurance representatives, HMO's, PSRO's, comprehensive health planning agencies, hospital and medical societies, so that the broad needs over a considerable length of time and the ultimate costs of diagnosis, continued treatment and follow-up are given attention via the hospital bed, outpatient department, health center, occupational-connected

medical department (that is in industry) schools, transportation needs, health care, and underwriting of costs are all included in community or regional planning and implementation. And certainly not everybody can afford \$200 just for one muscle biopsy.

- (12) Develop consumer advocates to assist the patient and family and to listen to him or her in recognizing self-needs and sources of help and bringing to the attention of elected representatives the need for public, social, political and economical concern for this leading group of costly disorders. Many arthritics do not seek or continue under long-term care because they cannot afford it.
- (13) Support the development of special centers equipped to study the newer intersystem relationships of disease and wellbeing as exemplified by chemotherapy, immunotherapy, etc., as well as specific mechanical-electrical aids and surgery.
- (14) Encourage group projects utilizing the voluntary arthritis groups and those associated with public health and preventive medicine.
- (15) Emphasize to preventive medicine, community medicine or public health departments and public health schools that chronic disability need not be complete, needs specified attention may be prevented or arrested and the quality of life improved for over 50 million residents of the U.S.A.
- (16) Use of carrot or club psychological approach to state and local departments of health that they give rheumatic and allied diseases a higher priority. Money seems to be the answer and is proven by the public still supporting emotionally the diseases or injuries which affect them; for example, cancer, heart disease, lupus erythematosus, epilepsy, Huntington's Chorea, multiple sclerosis, hemophilia, blindness, diabetes, Tay-Sachs disease, sickle cell anemia, Women Against Rape, "Women's Lib," etc. The categorical approach is still with us and has consumer meaning in spite of comprehensive, esoteric, objective, planning and primary care notwithstanding.
- (17) Encourage the PSRO, the utilization review groups, health service area councils, hospital and nursing home licensure agencies to include specific standards and evaluation of how rheumatic disorders are cared for in continuum and on a community basis and not just within the walls of one facility.
- (18) As is encouraged in the National Cancer and Social Rehabilitation Plan covering 17 comprehensive cancer centers in the United States, assist in setting up WAIS lines or other mechanisms for providing accurate, fast information to patients or other public as to the value of certain remedies, safety and accuracy of tests, referral of adequate quality sources of diagnosis, treatment and rehabilitation and sources of assistance for social, emotional and financial problems related to the rheumatic disorder. With time comprehensive, on-line information centers

with proper training of personnel, could be set up for many chronic illnesses as part of health education, continued education and self-help toward personal health maintenance.

- (19) Encourage the development of a governor's task force on arthritis for Pennsylvania.
- (20) Develop data banks of use to the consumer and with privacy of information regarding the patient.
- (21) Expand support for basic research in rheumatic and allied disease.

ENGLEMAN: Any questions from members of the Commission? Yes.

MELICH: I am particularly interested in your development of consumer activity programs. How would you do that? How would you recommend that?

PFEIFFER: Well, there are a number of ways that this might be provided, but I think the one starting point would be the kind of a project that has been started in my own chapter. There could be members of a local council or a local health department--and this certainly should be done on a local basis, even though, for example, in Pennsylvania we have a governor's number where anybody can call in free, where anybody can call for information, lodge a complaint or get assistance on a state-wide basis.

But I think in terms of having individuals in some type of agency setting, it could vary. The health department would be a perfectly possible place if there are health departments around. The voluntary arthritis agencies would be a source. Local planning agencies would be a source.

If people called in and said they couldn't afford a certain type of treatment, or they didn't know where to go for physical therapy or rehabilitation, or they couldn't find a job because they were being discriminated against on the basis of having arthritis, or they couldn't get insurance, the person on the other end of the line would be able to put that individual in touch with someone who could help him.

It's somewhat related to the WATS line idea where trained individuals are given quite a broad spectrum of information, and then they write down the questions they can't answer and see to it that the proper authority furnishes the inquirer with this information.

MELICH: (Inaudible)

PFEIFFER: Well, and such advocates to lead the activists in terms of increasing the amount of awareness both in the political sector as well as in the community in terms of what arthritics need and various kinds of concerns.



MELICH: Yes. I was wondering--you're talking sort of as a hotline, in other words, (inaudible) particular places and other additional information.

PFEIFFER: That's one form, but, of course, there are many other ramifications, that is, short of extreme activism.

ENGLEMAN: Dr. Sharp.

SHARP: Dr. Pfeiffer, I wonder if you could give us your own feelings about what one recommendation or program you believe would have the greatest impact on the care of the arthritic patient in central Pennsylvania?

PFEIFFER: So far as the care of the patients are concerned, I believe that the greatest deficit is in the area of providing home help, particularly physical therapy, occupational therapy, and seeing that transportation is provided, and getting these individuals also under the care of a rehabilitation center.

We have one rehabilitation center at Bloomsport which is very good. And in my own program we have given them some money for scope evaluation and rehabilitation. And some of that money goes (inaudible) in the community and helps provide some help for arthritics.

But being in a rural area, once a patient goes home, that's the end of it. There's nobody to follow up a person into the home to provide education or family support.

SHARP: In terms of really changing the situation, though, dramatically, I guess what I was getting at is, do you feel that establishing a rheumatic disease unit at the medical center or bringing in more rheumatologists as leaders in this region, do you feel that that would be the most important first move, or do you feel that the non-rheumatologists, other professionals could go ahead and make considerable progress in this region without having that type of leadership?

PFEIFFER: Well, I don't think it's a question of either/or, and one can't get these other helpers overnight either. So I think the profession itself needs to be upgraded and made more aware of what the potential is for the treatment, and for earlier treatment of patients with arthritis, and that they, in turn, could help to meet certain demands with other paraprofessional personnel.

ENGLEMAN: Thank you, Dr. Pfeiffer. Let's go on. Mr. Ballangee?



TESTIMONY OF  
JAMES M. BALLANGEE  
CHAIRMAN, EASTERN PENNSYLVANIA CHAPTER  
ARTHRITIS FOUNDATION

BALLANGEE: Thank you, Dr. Engleman.

My name is James M. Ballangee. I am the chairman and president of a large industrial and utility corporation in the Philadelphia area, and I am Chairman of the Eastern Pennsylvania Chapter of the Arthritis Foundation headquartered in Philadelphia.

I should like, however, to make my remarks today from the viewpoint of business and industry and from the perspective of one who has been afflicted with rheumatoid arthritis for more than a dozen years. I take this direction because I know in the course of your hearings across the country you will hear the viewpoint of many of those from local chapters of the Arthritis Foundation, and I seek to avoid some redundancy in what you must necessarily hear in the course of these hearings, and also because so many of our leading physicians have been active in our Arthritis Foundation in Philadelphia, and leaders in the country--indeed, you've already heard from Dr. Hollander--and Dr. Tourtellotte and Dr. Ehrlich will be here later today, as I understand, to make their statements.

It seems to me that one of the most overlooked aspects of arthritis, which has been alluded to by a speaker earlier this morning, is its effect on the productivity of labor and management in our industrial system. It's strange to me that the emphasis in our local foundations, indeed, even in this Commission, avoids the business aspect: rheumatoid arthritis and arthritis generally, in all its forms, has just been left to the rheumatologists and the members of the Commission.

I think business and industry need to be involved as they are in so many other programs. It's strange to me because the founder of our Arthritis Foundation is one of the great business leaders, at this stage of his career, in this country.

The chairman of our national chapter is a top officer in one of the major investment banking firms on Wall Street. And there are business people involved in various chapters, not as many, I think, as we need. And I think the reason is we have not pointed out to them their loss.

I've never been made aware of any study--despite the fact that people say "1 in 11" or that there's 20 million--any specific study that tells us how much productivity our nation is losing as a result of the debilitating effects of the various forms of arthritis.

Even with the highly expert treatment that I continue to receive, I could not, were I so talented, be productive as a typist, a surgeon, a musician or in any number of other lines of work. Fortunately, I happen to have a position in which I can maintain my productivity. I hope so. At least the stockholders seem to think so each year.

How many are there in that situation? I think we need to know. What is the cost, specifically, to this country, in lost production, lost wages and lost taxes? I believe the dollar amounts we are losing are substantial. I think we need to know for two reasons:

1. Once the corporations understand the dimension of the loss to them, I believe they will put strong emphasis on company programs for arthritics. They continue, as we do in our company, to support programs related to alcoholism not only because lives are saved, but it's strongly because costly absenteeism in industry is significantly reduced. And I think the same thing could be proven for arthritis with a sufficient study, and we could get support.

We won the award--in a hotel of this same name in Harrisburg in my company 2 years ago which I was privileged to accept--for employment of the handicapped. Arthritis was never mentioned at that time--never heard of. And I know we have a number in my company--in various companies, other than myself, and that we're losing productivity and time. But there's never been a study in my company, or any other than I know of, that specifically tells us what it's costing us.

2. I suspect that the loss of wages and taxes is enormous. If that is the case, then this Commission would be in a position to demonstrate to the Congress that any appropriations--whether for education, for treatment or for research--will almost certainly be returned over and over again in the form of taxes.

But no matter how valid my reasoning may prove to be, we still need the facts: Where? How much? How much productivity are we losing in this country because of arthritis?

A few congressional appropriations may be emotionally inspired, as the letter we heard this morning from the patient, but most are not. And, in my experience, nearly all corporate executives insist on empirical evidence before investing money or manpower.

I believe that this Commission is in a unique position to compile these needed figures, and I urge you to place this high on your agenda for action.

If I may, I should like to take just a moment to reflect my point of view as a patient. I'm certain that I am not typical, particularly after hearing some of the discussions about central Pennsylvania this morning, because I am so fortunate to live in an area that is one of the great medical centers of this country. Philadelphia educates 7 to 8 percent of the physicians graduated each year in the United States. A number of the nation's leading rheumatologists, starting with Dr. Hollander, are located in our area.

As chairman of a large community hospital for a number of years, and continuing as chairman of this joint conference committee, I've been able to learn of and closely follow the developments in the treatment of arthritis.

And, finally, the cost of regular treatment has been well within my means. My company even has, though I must give credit to the union for starting this, along with our Blue Cross and Blue Shield and some other things, a paid prescription plan so that more than a month's supply of Indocin only costs me 50\$.

Quite naturally this was inspired (inaudible) medical care, Dr. Engleman, by people in California. It started there, and, in fact, I think the paid prescription insurance company--and I think this is a movement that can be tremendously helpful to many people--it's cost without a union contract is precisely the same as a dental care plan, or the Blue Cross or the Blue Shield, or the pension or retirement or whatever. And we got more commendations, particularly from retirees in our company who we allowed to be included in the plan because of that.

Thus, from my standpoint, then, as a patient, there is little needed in the way of teaching, grants or a new clinic or even public information, from a personal standpoint, about the availability. I don't need to know any more about the availability of clinics and treatment. All these things are needed by many others who need the professional help that I already enjoy.

I know all these items will be high on your list of priorities, but I ask you to emphasize the need for research. Obviously, it's the only ultimate answer. I have treatment: I want someone to find the cure. Anything less is simply a holding action that will help but never heal. Research must come first.

While we may not have enough training programs or treatment facilities, they do exist. They can and should be scattered across the country and be sponsored locally in like manner.

Research, however, in my view, needs funding in such substance that Federal grants, it would seem to me, would be the only practical method.

I urge this Commission to set as its highest priority the establishment of a national research effort, funded through the Congress, working toward finding the cause and the cure of what we all know to be the nation's number onecrippler. Thank you very much.

ENGLEMAN: Thank you, Mr. Ballangee. Any comment or questions from members of the Commission?

ANTHROP: Well, I'm on the Education Committee and at our last meeting in San Francisco we discussed industry and educating industrial people not only in what you discussed, giving the word to the potential arthritic, but also building buildings for the handicapped, ramps and rails, and raised toilets in public toilets, and possibly better ways of getting people up onto airplanes, because so many of our elderly arthritics travel. We also discussed home devices that could be used and designed by industry in such a way that the handicapped could find it much easier. So this is just a small portion of what we discussed. I'm sure the others up here have more statistics on what you wanted to know.



BALLANGEE: My point was, and I think business and industry follow the adage of, "Be selfish." That's the only thing that makes the world predictable. But we must demonstrate to them that they have something to gain, as has been demonstrated in programs of alcoholism and in many others such as employing the handicapped. We have never done this. There's never been any arthritis focus or emphasis towards business and industry that I've ever seen that has been effective. I think the reason is that we don't have enough facts and figures. We don't get corporate support in the way that we should in the Arthritis Foundation and others because they haven't been made aware of it, and they're not aware of what it's costing us.

ENGLEMAN: Dr. Batchelor.

BATCHELOR: The time frame in which the Commission is working is so short, the interest in some of the figures you mentioned is so great, that I venture to ask you whether, from your own interest in the impact of this illness on business productivity, whether, in fact, you are aware of any compilation existing today--and we are not in a position to go out and develop these surveys--and where any effort has been made? We certainly would appreciate knowing about it.

BALLANGEE: Dr. Batchelor, I do not know of any currently. I think it would have to be a national effort. And I think this Commission, in my view, should go back to the Congress and ask for the funds to develop that kind of study. Once that were done, we would have something to really take to business and industry and the unions and say, "Here's the proof of what is being lost," and back to Congress in the way of taxes that are lost.

The productivity of our country is getting increasingly important, particularly as we see nations around the world that have a higher productivity, and suddenly now have resources that we thought we were supreme in--energy and other things. We're paying more for that. Our only way to keep up competitively is through productivity.

We cannot afford to lose as many people as we're losing--either part-time or not being able to do a fully efficient job even though they may be getting paid for it--as we are with arthritics. But I don't have the facts and figures and I don't know where to find them, and that's my point this morning.

LEWIS: Don't you feel that industry and the unions and some of their efforts could begin some studies to show the effect of arthritis and its effect on productivity?

BALLANGEE: The problem that I see there, Mrs. Lewis, is that there are so many competing demands. If you went to the United States Chamber or the National Association of Manufacturers or the Association of Self-Insurers and Workmen's Compensation or the AFL-CIO, there are competing demands for their time, their manpower and their money in so many areas.

And I think it would be very difficult to be persuasive that they ought to appropriate when there's been a recessionary period for many.



They've cut back their memberships in chambers and many other things in business, I think.

I think we've got to find some way to demonstrate the evidence to them, and then we'll get support. I don't know how the people in alcoholism get them, but they certainly have their figures. I think there was a national study for accident cost of labor for the Department of Commerce in Washington.

ENGLEMAN: There are actually some figures. There have been studies performed regarding productivity and the effect of arthritis on productivity. It hasn't paid off so far. These figures are old. They're dated about perhaps 10 years ago.

GAY: Mr. Ballangee, it seems to me as though the payoff on productivity studies would be studies by type of work. As you pointed out yourself, productivity studies for a miner might indicate that this is a rather bad thing for him to do. And, in fact, this might, to some extent, steer the way you were going in retraining people who had arthritis. I think that productivity studies would have to be done on a rather large scale and by types of work.

BALLANGEE: Well, I'd certainly agree they'd have to be done by industry and then job description. But I think the payoff would come in that industry would then support programs for treatment of people who could then resume perhaps 80 or 90 percent of their full effectiveness and productivity at work when they're losing it now.

I have--it is only a hunch of mine--but watching some of the people that I know who have rheumatoid arthritis that work in my company with whom I've discussed it in following their careers, I think we're paying them the full amount, but I don't think we're getting the full productivity from them, except those few that are taking treatment and have their condition in a status that's fine. We've transferred them into positions that they get because I happen to know about it, and I happen to have a personal interest. I don't think that's being done in many other places.

ENGLEMAN: Thank you very much, Mr. Ballangee.

BALLANGEE: Thank you, Dr. Engleman.

ENGLEMAN: Dr. Glauser.

TESTIMONY OF  
FELIX GLAUSER, M.D.  
PLANT PHYSICIAN, BETHLEHEM STEEL

GLAUSER: I am Dr. Felix Glauser, and I am the plant physician for Bethlehem Steel in Steelton, Pennsylvania. And I speak as one who labors in the trenches, seeing a great deal of arthritis firsthand.

This condition impacts on industry in three fashions primarily: First, we see them as job applicants, we see a great many. Second, we see those who come in who have developed the arthritis after being employed. And, thirdly, we see arthritis as a complicating factor in those who have been injured in the course of their work. In all three cases my problem is one of frustration. I have nowhere to send them. There is a large lack of expertise in this area.

And to answer Dr. Sharp's question of a few minutes ago, if I had my choice I would like to set up centers where I know an expert opinion could be given on this matter and treatment instituted. That is my major frustration.

ENGLEMAN: Thank you very much, Dr. Glauser. As a spokesman for Bethlehem Steel, is it possible that Bethlehem Steel would be willing to alleviate the frustrations to which you refer?

GLAUSER: Doctor, if you knew how far down on the ladder I was, why, you wouldn't ask me that question. They rarely call me in on policymaking decisions.

ENGLEMAN: You have a medical department in Bethlehem Steel? You're a member? Are you--

GLAUSER: Yes, we do, and it's centered in Bethlehem.

ENGLEMAN: Yes. You've discussed this with the heads of your department?

GLAUSER: No, I never have discussed the matter of arthritis with them. However, it may be helpful, taking up the matter of alcoholism, which has been mentioned two or three times before; this subject has been discussed, and we have salvaged a great many alcoholics, and we're very accurate on that matter. And if the same thing could be done with arthritis, why, a great stride forward would be made, no question.

ENGLEMAN: Well, it just seems to me that--and Mr. Ballangee, of course, raised this same point--that if industry only knew how they were hurting because of this problem, then industry might do something. But there are adequate data that already indicate this, and I'm not impressed by what industry is doing.

GLAUSER: As far as arthritis is concerned, they're not doing anything that I'm aware of.

ENGLEMAN: Yes.

SHARP: Dr. Glauser, you point out that there are areas of need in Pennsylvania where there is not enough expertise, and you suggest setting up new centers. I wonder if we could hear from you or Mr. Ballangee, or anyone, what has the State of Pennsylvania done in terms of utilizing the strengths that do exist? What kind of relationship is there between Philadelphia and Pittsburgh and central Pennsylvania in regard to some of these strengths? How are they perhaps brought to bear or not brought to bear in relatively deprived areas?

GLAUSER: I'm sorry, I cannot give any positive answer to that question. I know a few rheumatologists about central Pennsylvania because I know them personally. If I didn't know them I would be cut off completely.

LAWLESS: Dr. Engleman?

ENGLEMAN: Yes.

LAWLESS: Dr. Glauser, in terms of hiring, what's the status of a diagnosis of arthritis? Is that a barring factor?

GLAUSER: No. The Federal Government has put through new rules concerning the hiring of the handicapped, and we follow them very rigidly. And if someone does have arthritis, I am to evaluate how severe it is and what jobs they can and cannot do, and then I recommend to the employment office that they be hired with certain restrictions. Don't forget, working in a steel plant--it's a rough place to work. I know I couldn't work there except as a physician. The employment office then makes the decision as to whether they have a job for the man with that restriction.

LAWLESS: But you say it's a functional restriction that you decide?

GLAUSER: Yes, I decide.

ENGLEMAN: Thank you very much, Dr. Glauser. Dr. Shulman?

TESTIMONY OF  
LAWRENCE SHULMAN, M.D.  
STAFF, JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE  
JOHNS HOPKINS HOSPITAL

SHULMAN: Dr. Engleman, members of the Commission:

I come from the neighboring State of Maryland, specifically from Baltimore, where I'm associated with the Johns Hopkins University School of Medicine and the Johns Hopkins Hospital, and I've been concerned with their rheumatology programs over the past 4 years. I've also had the privilege of serving, just this past year, as President of the American Rheumatism Association, our national professional society.

I would like to speak to you just to give you some personal views on one given thorny area in terms of your deliberations: namely, the question of centers. I will have no specific guidelines to recommend to you, only



some general thoughts about this very difficult area--a very challenging area for you as the legislation is written, I would grant.

I think one of the questions about centers is the matter of definition. It's sort of a frightening term, indicating something rigid. I think rather that it's important to think of this as groups or teams of individuals to do certain tasks. Certainly, we need groups and teams of individuals to carry out research, both of a basic and applied nature. We certainly need groups of individuals to carry on our educational mission, both professional education and, equally important, public education. Also, we need groups of individuals to deliver certain types of sophisticated patient care.

We need, as you all know, a wide number of professions concerned with the care of the arthritic patient. What we really need are the most efficient groupings of people with different talents to carry out the several missions, each important, that you are now formulating--first, in terms of their own workshops and work groups where they are actively at work; and, ultimately, these very important decisions can be made by you, the Commission itself.

I think we'd want to ask the question: What do we want to have in the rheumatic disease area by 1980, by 1985 and by 1990? We must ask these long-term questions. Certainly, as Mr. Ballangee so eloquently presented to you, we need major advances in such areas as rheumatoid arthritis and in systemic lupus erythematosus, a very serious disorder with which we deal in many people. We need major advances in research similar to those that have actually been made in the area of gout.

The gout story is a fascinating one that needs to be underlined. So much is known about the cause and treatment of gout that has been made known in the past 15 years by research supported nationally and locally, that this is a disease that is now thoroughly manageable. It is a disease, by the way, that affects a million people in the United States.

We need, of course, to apply the research knowledge that we have now. Our educational mission is huge. Certainly, we need to instill as much knowledge as possible concerning the rheumatic diseases in each physician or nurse--each person who will be seeing the patient first, the arthritic patient. Therefore, we need an excellent medical educational program in each medical and nursing school in order to insure that they will have the knowledge that is required to know what to do for the patient when he first develops arthritis.

Then we need education for experts who can make the right diagnosis in a difficult situation and then recommend the right type of therapy in a difficult therapeutic process. And we need education for research, research experts, if you will.

We need a tremendous increase in public education. The public needs to have a totally different view of arthritis than they have today. They need to be made aware of the problems and the opportunities in the arthritis field. It must be emphasized to the public that we're not dealing with one disease of the elderly, as many people think, but we're



dealing with a whole host of different diseases for which the natural course varies and for which the treatment, most importantly, varies hugely.

We also want to see by 1980, '85, '89, and '90, that the patient can get the ready access to health care that he or she deserves and that they get the right diagnosis and treatment given to them. For that we have to have a great increase in the number of personnel in many different categories, and we need to have them properly distributed. We have some data on personnel needs at the moment, but it's far too fragmentary, and there's a great need for much more.

We need to concern ourselves with referral patterns with respect to patient care, and we do need demonstration centers as to what is best to do in terms of patient care. Now we don't need to start from scratch. An important thing to emphasize is that, as we think about centers, we need to build upon what we have now.

We also need to renew the momentum in the arthritis field. In the past 14 years, from '55 to '70, there was a huge momentum in the whole area of arthritis and related diseases. And this is a lot of work, but a fragment in terms of the programs by which we can really deliver the goods for the patients with arthritis nationally. We need to renew all the serious programs that will be concerned with an upward movement for the whole arthritis field that I outlined earlier.

Now as to the question of centers, I think that they're absolutely essential. One question has been asked: Well, do we need any centers at all? I think we need groups, teams, centers, as it were. We obviously need a critical mass of people to meet the various missions that we've been talking about and that you will be discussing. This field demands that there be a center. There has to be a base of individuals to provide the education that's so sorely needed. We need to have a base of individuals which will provide, in areas all over the country, the expert or sophisticated care that some patients with arthritis require.

I think also that we don't need a prototype of a center, but rather we need different types of centers. Some centers would specialize in orthopedic treatment and orthopedic research; others should specialize in rehabilitation; others would specialize in pediatric problems related to arthritis.

Then there may be other types of different thrusts or missions that centers could have. One could be a center devoted to research on rheumatoid arthritis; another to research and treatment of lupus, systemic lupus erythematosus; another devoted to the spondylitic group, an exciting new area in our field.

We need centers. We need centers that have built-in evaluation. We need to evaluate the centers as we create them. Also, most importantly, we need some flexibility in our centers as we create them, not only diversity but flexibility in the centers, in order to take advantage of new discoveries as they come along. For example, a very exciting new discovery of a specific tissue antigen, HLA-27, W-27, 27, in the whole

area of arthritis. These are various forms of arthritis in young people. The development of a national network of centers could take advantage of this new discovery in a great way.

In terminating, I would say that we have so much to do. I would hope and trust that you, in your wisdom, will set your priorities with great talent and great vision, and I know you will do that. Thank you.

ENGLEMAN: Any comment or question from members of the Commission? Yes, sir, Dr. Sharp.

SHARP: Dr. Shulman, I wonder if you could just briefly elaborate on your comment, "We should build on what we have now in starting the centers," particularly in terms of great distributional problems that exist in this country?

SHULMAN: What I meant by that was that one of the questions that we've asked is: Do we have centers now? I say that we have almost centers, to varying degrees, in several different places throughout the country. Instead of starting new centers, I would say we ought to give that amount of support that will complete the job.

In contrast, where there are no centers or no groupings of individuals, no people with the talents required to take care of the patients, we'll have to start from scratch and build what is necessary and is best for that particular area.

SHARP: That would take some manpower--

SHULMAN: Yes, sir, it would take a lot of manpower.

SHARP: --which we may not have at this point.

SHULMAN: And that's why we need the educational programs, Dr. Sharp.

LAWLESS: Dr. Shulman, I have a question. One of the problems is a tremendous disparity of service between university-public versus the periphery.

Do you perceive some function of the center as a coordination device for the delivery of health care services? In other words, how do you get that sophistication out to the community in a system where--we've heard from some of the chapter members here--in one area in Pennsylvania there's sophisticated care; in another area, no personnel but maybe some paramedical personnel. How do you bridge that gap in delivery of those services that are needed?

SHULMAN: Well, Dr. Lawless, you've asked an extremely difficult question, a question that will require the talents of those who are concerned with health care.

Very strongly within the university is a sense of community responsibility. There are departments of community medicine within

universities that are concerned with the outreach that we all think is so necessary.

I think one of the questions there is: What type of rewards can be provided to fill these gaps? I think that building certain rewards would help to do that.

ENGLEMAN: Do you want to give us a round figure as to how much you think these centers might require?

SHULMAN: No, sir. I wouldn't at this time because I would be better able to do that after seeing the reports of your meeting as to what the needs are.

ENGLEMAN: Would you rather see 40 centers or 10 centers, if you had your choice? That is with the same amount of money.

SHULMAN: I'll respond to that. I think I would prefer to see 40 centers.

ENGLEMAN: Okay. Thanks very much. Dr. Tourtellotte.

SUBMITTED STATEMENT OF  
CHARLES D. TOURTELLOTTE, M.D.  
MEDICAL DIRECTOR  
GREATER DELAWARE VALLEY REGIONAL MEDICAL PROGRAM  
ARTHRITIS CONTROL PROJECT

A pilot program for regionalization of arthritis resources has been undertaken to facilitate optimal diagnosis, treatment, and rehabilitation of arthritis patients. Major emphasis has been given to decentralized arthritis demonstration clinics (ADC) and professional education in an attempt to bridge the gap between investigations at clinical research centers and care available to patients. This program is somewhat unique in the balance and coordination of project components, the magnitude of mobilized resources, and the extent of regional utilization of programmatic activities by health care professionals and patients. Five medical schools and the Arthritis Foundation chapter have joined in a singular collaborative effort under RMP guidelines to permeate a 24-county area of Pennsylvania and New Jersey encompassing 7 million persons.

The Arthritis Demonstration Clinic component represents the major thrust of this Arthritis Control Program. Particular sensitivity is paid to local needs for improved delivery of services with arthritis activity being:

- (1) developed where non-existent;
- (2) improved where limited capability exists for skilled diagnosis, treatment, and rehabilitation;
- (3) strengthened where full capability and responsibility exist for care delivery and education.



In each Arthritis Demonstration Clinic there is full utilization of additional programmatic components and resources (physician continuing education, allied health professional training, pediatric services, patient-family awareness and arthritis screening). Approximately 400 physician hours per month are devoted to formalized instruction such as preceptorships and lectures in 17 sites throughout the region. Exemplary patient care and education are provided as a part of the ADC activity to 250 persons per month. The standard data base for rheumatic disease is being implemented as part of a cooperative activity with ARAMIS. A self-assessment examination has been developed in an attempt to discern advancement of physician knowledge of diagnosis and management of arthritis.

Last year 3 full-day continuing education seminars were held reaching over 300 practicing physicians throughout the GDVRMP region. Approximately 500 allied health professionals were provided training through three full-time regional seminars and specialized inservice arthritis training. The pediatric component trained 41 physicians, 32 nurses and 35 therapists in specialized arthritis care for children in addition to its current education role and implementing a uniform case record system. For this year, each component is expanding its activity to reach an even greater number of health personnel for arthritis care training.

It is concluded that an arthritis control initiative as formulated here by the Greater Delaware Valley RMP, the Arthritis Foundation of Eastern Pennsylvania, the five Philadelphia medical schools, selected community general hospitals, and practicing physicians can be successfully implemented.

The Arthritis Control Program of the Greater Delaware Valley RMP is a model which has begun to build an efficient and coordinated regional delivery system for improved arthritis care--the prerequisite for developing population bases for clinical research studies. Moreover, the relationships developed between practicing physicians and allied health professionals and those rheumatologists, orthopedists and physiatrists in the research settings of the medical schools is providing for timely dissemination and application of the latest clinical findings from research on the rheumatic diseases.

Based upon our 15-month experience with regionalization of arthritis care resources, we suggest the following to the National Commission as it considers proposals for implementation under the National Arthritis Act:

- (1) Successful arthritis regionalization programs must be given high priority for continued and expanded funding in order to develop increased capabilities for the delivery of arthritis patient care.
- (2) Arthritis programs must be designed and operated under the principle that continued and sustained support for arthritis-directed research derives most significantly from demonstrated patient care needs and improvements.

- (3) The role and participation of arthritis clinical research centers must be emphasized in regionalized arthritis programs with substantially increased funding for clinical research in arthritis diagnosis and treatment.

We thank the members of the National Commission for this opportunity to present information on the Greater Delaware Valley RMP Arthritis Control Program and these suggestions to be considered in the implementation of the National Arthritis Act.

Harrisburg, Pennsylvania

October 14, 1975

ARTHRITIS CONTROL PROGRAM  
OF THE  
GREATER DELAWARE VALLEY REGIONAL MEDICAL PROGRAM

LIST OF APPENDICES

- I. Summary of Program
- II. Program Brochure (not included)
- III. Pilot Arthritis Screening Methodology
- IV. List of Arthritis Demonstration Clinics



APPENDIX I

## SUMMARY

## THE ARTHRITIS CONTROL PROGRAM

## OF THE

## GREATER DELAWARE VALLEY REGIONAL MEDICAL PROGRAM

For the past 2 years the Greater Delaware Valley Regional Medical Program has been awarded grants to carry out a pilot arthritis program to begin building a coordinated delivery system for care to the approximately 800,000 arthritis sufferers in the region.

The design of the Arthritis Control Program has been based on the principle of regionalization of rheumatological resources through a multi-institutional effort to permeate the entire 24-county area. A unique collaborative effort joining the five Philadelphia medical schools with select community general hospitals and the Arthritis Foundation of eastern Pennsylvania has been achieved in the program activity and in the formation of its policy-making body, the GDVRMP Arthritis Control Program Council. Major activities are conducted at decentralized locations to establish new centers or to upgrade existing capabilities in arthritis diagnosis, treatment and rehabilitation.

There are six specific project thrusts:

(1) FACILITATING THE DEVELOPMENT OF ARTHRITIS DEMONSTRATION CENTERS

- To strengthen and upgrade existing care programs for 17 sites throughout the region to promote eventual self-sufficiency in skilled arthritis diagnosis, treatment and rehabilitation.

(2) CONTINUING EDUCATION FOR PHYSICIANS

- To increase the awareness of family practitioners, internists, pediatricians and orthopedists for the multiple diagnostic, therapeutic, emotional and social problems of patients with rheumatic diseases.

(3) TRAINING ALLIED HEALTH ARTHRITIC CARE TEAMS

- To develop and conduct training courses to upgrade a variety of allied health professionals to provide for collaborative relationships and to promote an interdisciplinary team approach to arthritis care.

(4) PATIENT AND FAMILY AWARENESS

- To create an awareness on the part of arthritics and their family members of the nature of rheumatological diseases and their impact by providing resource interventions to assist in the

economic, psychological and physical adjustment to the home, employment, and community environment.

(5) PEDIATRIC ARTHRITIS INITIATIVE

- To upgrade three pediatric arthritis clinics and lend support to the arthritis demonstration clinics throughout the region to provide the specialized sensitivities necessary for the management of arthritis in children.

(6) PILOT ARTHRITIS SCREENING METHODOLOGY

- To develop a valid and inexpensive technique of screening people and identifying arthritics in selected populations throughout the region and to refer those detected to appropriate medical resources.

In order to operationalize these program objectives, the GDVRMP Arthritis Control Program has mobilized a variety of resources concerned with the rheumatic diseases. The program utilizes personnel from Temple University Health Sciences Center, Medical College of Pennsylvania, Hahnemann Medical College and Hospital, University of Pennsylvania School of Medicine, Albert Einstein Medical Center, Moss Rehabilitation Hospital, Thomas Jefferson University Medical College, the Children's Seashore House and the Arthritis Foundation of Eastern Pennsylvania. Additionally, program support is rendered from several physicians affiliated with the Medical and Scientific Committee of Eastern Pennsylvania Chapter of the Arthritis Foundation.

Address inquiries to:

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APPENDIX III

PILOT ARTHRITIS SCREENING METHODOLOGY PROJECT

Director: Joseph Lee Hollander, M.D., Professor of Medicine  
University of Pennsylvania School of Medicine  
Philadelphia, Pennsylvania.

The Pilot Arthritis Screening Methodology Project represents a major innovative effort to develop a valid and inexpensive technique of screening people and identifying arthritics particularly so that proper medical advice may be given to prevent crippling and deformity. A questionnaire has been developed to provide optimal arthritis case finding. Various means are being employed in sampling selected populations throughout the GDVRMP region. This project is being conducted by the Eastern Pennsylvania Chapter of The Arthritis Foundation.



APPENDIX IV

GDVRMP ARTHRITIS CONTROL PROJECT

LISTING OF ARTHRITIS DEMONSTRATION CLINICS

Hahnemann Medical College Program

Chester-Crozier Medical Center, Chester, Pa.; Thomas Beardmore, M.D., Director

Wilkes-Barre General Hospital, Wilkes-Barre, Pennsylvania; Thomas Beardmore, M.D., Director

Jefferson University Program

Lankenau Hospital, Philadelphia, Pennsylvania; John Abruzzo, M.D., Director; Bonnie Doward, M.D., Assoc. Director

Medical College of Pennsylvania Program

Montgomery Hospital (Sacred Heart Hospital), Norristown, Pennsylvania, Warren Katz, M.D., Director; George McLaughlin, M.D., Associate Director

University of Pennsylvania Program

Children's Seashore House, Atlantic City, New Jersey; Balu Athreya, M.D., Director

Children's Hospital, Philadelphia, Pennsylvania, Balu Athreya, M.D., Director

Temple University Program

Abington Hospital, Abington, Pennsylvania; Robert Gatter, M.D., Director; Ronald Andrews, Associate Director

Allied Services Institute, Scranton, Pennsylvania; Charles D. Tourtellotte, M.D., Director; Michael Aronica, M.D., Assoc. Director

Cooper Hospital, Camden, New Jersey; Sheldon Solomon, M.D., Director; Brian Grimmett, M.D., Assoc. Director

Fitzgerald Mercy Hospital, Darby, Pennsylvania; H. Ralph Schumacher, Jr., M.D., Director; James S. Faires, M.D., Assoc. Director

Millville Hospital, Millville, New Jersey, Charles D. Tourtellotte, M.D., Director; William Fithian, M.D., Director

Monroe Co. General Hospital, E. Stroudsburg, Pennsylvania; John H. Martin, M.D. Director; Elmo Lillie, M.D., Assoc. Director

Philadelphia College of Osteopathy, Philadelphia, Pennsylvania (program pending) Albert DiPiero, D.O., Director

St. Christopher's Hospital for Children, Philadelphia, Pennsylvania, Charles D. Tourtellotte, M.D., Director, Donald Goldsmith, M.D. and David Smith, M.D., Associate Directors

Vineland Hospital, Vineland, New Jersey; Charles D. Tourtellotte, M.D., Director; Frank DeMaio, M.D., Associate Director

TESTIMONY OF  
CHARLES D. TOURTELLOTT, M.D.  
ACCOMPANIED BY J. WARREN SALMON  
DIRECTOR, GREATER DELAWARE VALLEY REGIONAL MEDICAL PROGRAM  
ARTHRITIS CONTROL PROJECT

TOURTELLOTT: I'd like to go ahead. I'm joined this morning by Mr. Salmon.

Members of the Commission:

I am a professor of medicine and Chief of Rheumatology at Temple University School of Medicine in Philadelphia. And for the past 16 months I have, in addition, been the Medical Director of the Greater Delaware Valley Regional Medical Program, Arthritis Control Project.

I am joined this morning by Mr. J. Warren Salmon, who is Assistant Professor of Community Medicine at Hahneman Medical College in Philadelphia, and who also serves as Director of the GDVRMP Arthritis Program. We'd like to share with you, the Commission, our experiences with this arthritis control project as a basis for the recommendations we wish to make this morning. Mr. Salmon?

SALMON: The Arthritis Control Program of the Greater Delaware Valley Regional Medical Program is a pilot program for the regionalization of arthritis resources undertaken to facilitate optimal diagnosis, treatment and rehabilitation of arthritis patients. Major emphasis is being given to decentralized arthritis demonstration clinics and professional education in an attempt to bridge the gap between the investigations at clinical research centers and the care available to patients. This program is somewhat unique in the balance and coordination of the project components, the magnitude of our mobilized resources, and the extent of the regional utilization of programmatic activities by health care professionals and patients. Five medical schools and the Arthritis Foundation chapter have joined in a singular, collaborative effort under the RMP guidelines.

TOURTELLOTT: In each arthritis demonstration clinic or center there has been full utilization of additional programmatic components and resources. These have consisted of physicians' continuing education, allied health professional training, pediatric services, patient-family awareness programs and arthritis screening. The details of these programs and some indication of the extent of the effort are dealt with more fully in the written text submitted to you.

Based upon our 15-month experience with regionalization of arthritis care resources, we make the following suggestions to the Commission to consider in its proposal for implementation under the National Arthritis Act:

- (1) Successful arthritis regionalization programs must be given high priority for continued and expanded funding in order to develop increased capabilities for the delivery of arthritis patient care.

2. Arthritis programs must be designed and operated under the principle that continued and sustained support for arthritis-directed research derives most significantly from demonstrated patient care needs and improvements.
3. The role and participation of arthritis clinical research centers must be emphasized in regionalized arthritis programs with substantially increased funding for clinical research in arthritis diagnosis and treatment. We thank you very much for considering our suggestions.

POLLEY: Thank you, Dr. Tourtellotte. Any questions from the members of the Commission? Dr. Lewis.

LEWIS: Do you see your regionalized project fitting very smoothly into the new health care system plan?

TOURTELLOTTE: Mr. Salmon is intimately involved in that kind of activity, and perhaps he could speak to that point.

SALMON: By "the health care system plan," I'm not quite sure what you mean.

LEWIS: The new National Health Planning and Resource Development Act.

SALMON: Yes, yes.

LEWIS: Program for 1974.

SALMON: The Greater Delaware Valley Regional Medical Program is intimately involved in the negotiations for the development of a new health systems agency. We, in our Arthritis Control Program, are trying to establish arthritis programs in each of the four developing HSA-designated areas, and we intend to carry out the kind of program that they've incorporated in their plan for overall health services.

POLLEY: Dr. Jenner?

JENNER: It may be in your written testimony, but what area does this regional activity cover, and about how many different organizations are you dealing with?

SALMON: Our area of the Greater Delaware Valley Regional Medical Program is a 24-county area of eastern Pennsylvania and south Jersey. It's somewhat coincident with the Eastern Pennsylvania Arthritis Foundation Chapter, in the eastern Pennsylvania area.

The organizations that are involved in our specific program include the Arthritis Foundation chapter and the five Philadelphia medical schools. We're using staff support from each of these areas, and also a few community general hospitals as well as a number of practicing rheumatologists who are in private practice throughout the region, and trying to develop a demonstration clinic with their assistance.



JENNER: Have you had to make any special considerations of the fact that you're moving across state lines; that is, you have several states involved?

SALMON: Not particularly, simply because we've been able to piggyback on the Greater Lower Valley RMP's efforts to help us over the last 7 years or so.

JENNER: And the state works with the county?

SALMON: Yes, very much so, yes.

LEWIS: Are you working with the State Department of Health?

SALMON: We have had not very much contact with the State Department of Health, except in a minuscule way. We're trying to formulate some programs in conjunction with the bureau of vocational rehabilitation. So you see, this is one of the areas that we intend to work on somewhat this year.

LEWIS: Do you see the need for some type of cooperative effort, more with the State Department?

SALMON: Yes, most assuredly. We have had contact in trying to develop relationships with both Jersey and Pennsylvania, but they have not been followed through to the effort that we intend to.

LAWLESS: Just one question: Do you have any participation by non-rheumatologists, practitioners, in the community programs, and to what degree is the referral system working both ways?

TOURTELLOTT: To a considerable extent. We have involvement of all levels of the health care delivery system. This really represents a parallel activity between the medical school arthritis research centers, if you will, and practicing physicians and health care deliverers. So, in each area of our involvement in this program, we not only have university personnel--basically, rheumatologists, orthopedists and podiatrists--but the practicing physicians of the area. We have not gone into any area for establishment of our program where we didn't have grass-roots support by local organized medicine and physicians. That's the key to the success, or whatever success we may have realized.

ENGLEMAN: Yes, Dr. Sharp.

SHARP: I have three related questions. Of all the programs that you initiated which one do you, at this point in time, feel is the most successful--that's having the greatest impact on arthritis care in this region? Secondly, what type of evaluation process will give further information in that respect? And, thirdly, did you have any difficulties in terms of relationships with the community people and the medical professions in the communities in terms of accepting this relationship?

TOURTELLOTT: Probably the most successful aspect of the program is the Arthritis Demonstration Clinic, the decentralized demonstration

program in a given area. And that program was fitted to the individual needs of a given locale. So, where a program was totally nonexistent, we established one. Where you had a basic activity, we undertook to improve it. And so I'd have to say our Arthritis Demonstration Clinic concept, decentralized from the Philadelphia area, has been our most successful program under the total project.

Our evaluative mechanism, by the nature of the short time we had to develop it, and so on, is basically process-oriented; to a very small degree is it outcome-oriented, meaning, "Can we evaluate, in a significant way, how the physician is improved in his skills or how the allied health person is improved or how the patient comes out better?" But we have made some steps in this regard. For example, the development of a physician self-assessment examination that attempts to get at how our activities have improved his abilities.

Finally, difficulties. I think the program is difficult to implement if you don't have people of good will involved in its operation. So where our programs are most successful are those areas where we, as individuals or as medical schools or institutions, have laid the groundwork for their success. I would say we've been fairly successful.

SHARP: Well, that's the point I wanted to bring up, because I agree with you that, in general, these community programs will be most successful where you spend, really, several years developing the rapport with the community. In that regard, you say the arthritis demonstration clinic was fitted to the needs of the community. Who determined the needs of the community, you or the community?

TOURTELLOTTE: We did, in concert with the community, essentially.

SHARP: That's very, very important.

TOURTELLOTTE: Because if you do not, then the attitude is that you're bringing programs from on high, and they aren't viewed with very great receptivity.

LAWLESS: One other question: Is there any other system like this in the rest of Pennsylvania? This is just a regional area?

TOURTELLOTTE: Eastern Pennsylvania and southern New Jersey, too, are--well, he might know better than I. This is somewhat unique.

SALMON: Ours is somewhat unique simply because we were given a quarter of a million dollars to try to implement it over these past few years. I don't believe the other areas of Pennsylvania have received that level of funding, so they weren't able to undertake as large an activity.

LAWLESS: Has there been any interest from the other areas in your program? In other words, is that idea catching on within northern Pennsylvania?

SALMON: There's been a number of inquiries from various RMP-funded programs into different aspects of our program. We're running six

projects now, and we've had a number of inquiries. We've shared a lot in terms of what we've been doing in our pediatric services and in our patient-family awareness, and also in--some (inaudible) regionalization. We've been wading through a couple other programs.

SHARP: Could I ask another question? Have you been making any effort at a statewide arthritis task force or trying to bring your strengths to bear on some of the rest of the state?

TOURTELLOTTE: No. I can say we were prime-movers in trying to get all the RMP's to a common meeting in Kansas City to share our experiences. But I have to say we've been extremely busy and occupied with this activity. It's a tremendous drain on our vitality, and we haven't been able to see our way clear to coordinate statewide to any significant degree.

ENGLEMAN: Dr. Felts.

FELTS: Do you have any testimony as to the number of patients in your program who continue to receive fragmented care; that is, care for their rheumatic condition through your effort and primary care through their community physician through other efforts?

TOURTELLOTTE: Well, you have to understand that our program is not primarily a patient care supply program. It's a demonstration or a pilot project. And, so, in that sense, I have to say that the patient care need is only slightly being met, except in those areas where we have a demonstration clinic. As a result of an individual clinic's activities, however, I think that the coordination of resources is far better developed for our having been there. But to give any indication in a quantitative sense about these factors, I--we couldn't begin to--

FELTS: Well, I'm probing to get some indication from you, an assessment or professional reaction to your endeavor. Are your patients primarily self referred or physician referred? And how many physicians, percentage-wise, are participating?

TOURTELLOTTE: When we go into an area, we lay the groundwork with the professionals, and they generate the patients' referrals. When we go into an area where nobody has been before, the referrals come slowly. But as you make your educational impact, they come in droves, and that's generally been our experience.

FELTS: Well, is that coming in droves through professional referral or through patient referral?

TOURTELLOTTE: Through professional referral.

SALMON: In addition to that activity with the demonstration clinics, which Dr. Tourtellotte was talking about--and we have 17 of these now going in various parts of the county--we also have been running full-day continuing education seminars. Last year we had over 300 practicing physicians come to those programs.



We're expanding those this year because we did have a real ground swell of support from the practicing communities, physician communities. And we're trying to run four of those this year, each, again, decentralized, away from the Philadelphia medical schools, to the areas where the physicians practice. We've seen this as a really strong principle that's absolutely necessary to engage a number of resources in building a delivery system, which essentially has been our orientation--not necessarily patient care.

ENGLEMAN: The RMP support's going to terminate, unfortunately, in July. What happens then? Do you have any ongoing funding mechanism?

SALMON: We're caught in the same situation that we were in last year at this point in time of not knowing whether the funding wins.

ENGLEMAN: Well, I don't think there's that dilemma this time. I think it's pretty clear where it's going to go.

SALMON: Well, we're happy to know that.

ENGLEMAN: Well, I don't think you should be happy at all. In other words, there's no indication that RMP's going to be sustained. So my question is: Are you anticipating this lack of financial support as of July?

SALMON: We're anticipating trying to find some funds available, and, obviously, through the National Arthritis Act, we're supporting various aspects of the program. We would hope to possibly rely on some state funds for, again, different aspects of our program, as well as trying to move, possibly, the demonstration activity into third-party reimbursement to support the rheumatologists and the podiatrists and the orthopedists who may be going out into these outlying areas. And, obviously, continuing education, at this point in time, does not have to be subsidized by RMP funds.

ENGLEMAN: Ms. Anthrop, did you-

ANTHROP: Yes. I would like to know what part the nurse plays in this. Does she facilitate teaching or what?

TOURTELLOTTE: It varies, and perhaps Dr. Ehrlich, in his allied health comments, will speak more to this point a little bit later on in the morning.

The nurse has been an integral part of our interests in various ways. The seminars that we have are--have the nurse in mind. We also have several nurses on staff who are skilled in arthritis health care provision, and they are active in the educational aspects of the--

ANTHROP: In other words, they were trained before they came to you?

TOURTELLOTTE: Yes.

ENGLEMAN: Thank you very much, Dr. Tourtellotte and Dr. Salmon.

Cynthia Garry?

TESTIMONY OF  
CYNTHIA GARRY  
VICE PRESIDENT AND CHAIRMAN OF WOMEN VOLUNTEERS  
CENTRAL PENNSYLVANIA CHAPTER, ARTHRITIS FOUNDATION

GARRY: Good morning, ladies and gentlemen. I am privileged to be here. I'm Cynthia Garry, Vice President of the Central Pennsylvania Chapter of the Arthritis Foundation, and also the Chairman of Women Volunteers.

I'm an active mother, and I'm 33 years of age. For all of my 33 years I have watched the body of my mother, who is now 67, gradually become twisted and bent in her severe bout with arthritis.

On the 2nd of October mother entered the hospital for testing, and underwent surgery for a total knee replacement. Even though she was a substantial surgical risk, she chose this path because, with her, it is the only alternative to being bedfast for the remainder of her life.

Surgery could have been hazardous not only due to the fact that clotting may have been involved, but that kidney damage may have occurred since she has been on the maximum dosage of gold injections which can produce kidney deterioration and its side effects.

She is a great inspiration to all who know her with her positive mental attitude, and because of her I, as a volunteer with the Arthritis Foundation, will continue to strive to raise funds to combat and eradicate this very dreaded disease.

It is my personal wish, and the wish of my mother, that funds allocated by the government be carefully distributed for research to end the crippling, the suffering, the pain--arthritis itself. Thank you.

ENGLEMAN: Thank you, Ms. Garry. Any questions or comments from the members of the Commission?

(No response.)

ENGLEMAN: May we call then on Heidi Neiswender.

TESTIMONY OF  
HEIDI NEISWENDER, R.D.  
PENNSYLVANIA DIETETIC ASSOCIATION

NEISWENDER: Good morning. I am Heidi Neiswender, a registered dietician. I am here on behalf of the Pennsylvania Dietetic Association.

The Pennsylvania Dietetic Association represents approximately 1,140 dietitians and nutritionists who endorse the goal of the National Commission on Arthritis and Related Musculoskeletal Diseases. I thank the Commission for this opportunity to file the following statement.

We see great need in the area of improving and maintaining the general nutritional wellbeing of persons afflicted with arthritis and related muscular diseases. The professional expertise of registered dietitians and nutritionists should be used to counsel and guide these persons in the proper selection of food. In the selection of these foods, recognition must be given to the physical limitations of these persons and their abilities to open packages, jars, and cans and to cut up and chop food.

A decrease in activity by the persons afflicted with arthritis and related muscular diseases may be reflected in a decrease in their appetite or may be attributed to the problem of obesity. Therefore, interesting meal plans need to be provided that will help stimulate their appetites without contributing to obesity. For those persons who are obese, dietary counseling should be provided to assist them with weight reduction.

Nutritional counseling needs to assure that the diets of these persons provide sufficient iron intake to prevent the occurrence of any iron deficiency. Other problems related to diet such as diabetes, and hyperlipidemia can best be provided through dietary counseling. Assistance for shopping and budgeting for food should also be provided. Sound nutritional planning and counseling should also be used to combat food misinformation.

We urge that funds be provided to cover these nutritional services for persons afflicted with arthritis and related muscular diseases. Thank you.

ENGLEMAN: Thank you, Ms. Neiswender. Questions?

(No response.)

ENGLEMAN: We now call on Dr. Gerald Rodnan.



TESTIMONY OF  
GERALD RODNAN, M.D.  
PROFESSOR OF MEDICINE  
CHIEF, DIVISION OF RHEUMATOLOGY AND CLINICAL IMMUNOLOGY  
UNIVERSITY OF PITTSBURGH SCHOOL OF MEDICINE

RODNAN: Mr. Chairman and members of the Commission:

I, Dr. Gerald Rodnan, am a professor of medicine at the University of Pittsburgh School of Medicine, where I serve as the Chief of the Division of Rheumatology and Clinical Immunology in the Department of Medicine. I am grateful to you for this opportunity to present some of my views concerning the functions of the comprehensive arthritis centers which are to be established under the provisions of the National Arthritis Act. Although this Act outlines many very worthy activities to be pursued by these centers, emphasis is placed upon the conduct of basic and clinical research, professional training and public education. I believe that this emphasis is proper. I believe that reason and experience provide strong support for the view that the conduct of research and training would indeed be the chief functions of the centers.

In considering the importance of research, I cannot help but reflect upon the changes that have taken place in the field of rheumatology within my own lifetime. A year ago, I returned to my alma mater, the Downstate Medical Center, in Brooklyn, to take part in an alumni day program marking the 25th anniversary of my graduation from medical school. I'd been asked to speak on the subject of rheumatology then and now. In preparing to meet this interesting challenge, I returned to my textbooks of yesteryear and reread--or perhaps I should confess--read for the first time the sections dealing with rheumatoid arthritis and with gout. Comparing what I found in those tomes of the late 1940's to what is known about these disorders today, I was impressed by the extent of the changes that have taken place in the field during the past quarter century, changes that preoccupation with day-to-day problems make it difficult to appreciate.

The growth of rheumatology is exemplified by the rapid rate of discovery and elucidation of previously unrecognized or obscure syndromes requiring frequent revisions in the classification of the rheumatic diseases. In the primer on arthritis, published in 1942, for example, the domain of arthritis was encompassed in a list of less than three dozen disorders. In the seventh edition of this primer, published in 1972, the role of rheumatic diseases has tripled. It would take several hours, I am very happy to say, to begin to review the knowledge that has accumulated in the past 20 years.

I well recall that my own instruction as a medical student of the rheumatic diseases consisted of a 20-minute lecture. Little or nothing was known at that time concerning the pathogenesis of rheumatoid or gouty inflammation. And with the exception of aspirin, chrysotherapy and Colchicine, nearly all the medications--the use of which we now take for granted in the treatment and control of rheumatoid arthritis and gout--had yet to be discovered.

And how were they discovered? The answer, of course, is through research. If we are to improve the lot of our patients with arthritis, we must begin by being dissatisfied with the status quo; by having the desire to find a better and quicker way of recognizing and diagnosing rheumatic diseases in their early phases when treatment is likely to prove most successful; by seeking to understand the nature and cause of these diseases in order to develop more effective medications which attack the disease with a minimum of troublesome side effects; and by ultimately seeking the means to prevent or eradicate the disease. Knowledge gained through research means very little, however, unless it is taken from the laboratory to the bedside and clinic and applied directly for the benefit of the patient.

In this regard, it is essential to recall that fewer than 5 percent of individuals with rheumatic disease in this country are seen by a rheumatologist, and approximately one-half neither seek nor receive any medical attention at all. The remainder are under the care of family physicians or various other specialists, some of whom may have had little formal training in rheumatology, and many of whom, unfortunately, are unfamiliar with newer developments in this rapidly changing field.

Not a single state in the union possesses an adequate number of rheumatologists to meet what is considered a reasonable demand for consultation and services. If we are to attain our goal of exemplary quality of care for patients with arthritis, it is clear that we must not only train more rheumatologists but must also increase and improve the education of those primary care physicians who now see, and in the future will continue to see, the vast majority of those individuals who receive assistance from the medical profession.

This job begins logically in the medical school. Give me the boy, and I will give you the man. (Since my daughter's in medical school, I might add, give me the girl, and I'll give you the woman.)

Although the majority of modern medical students do receive instruction in the rheumatic diseases, there are, unfortunately, many schools in this country in which the program of undergraduate and graduate training is either unduly limited in scope or totally inadequate. In a recent survey, conducted by the Professional Education Committee of the Arthritis Foundation, it was found that, in 15 of 94 respondent schools, there were no arthritis training programs at all. Imagine, no instruction at all concerning a group of disorders which affects 15 to 20 million of our countrymen. We should seek to emulate our Canadian cousins, who are in the process of establishing rheumatology units in each and every medical school.

If we are to compete successfully with other subspecialties of internal medicine for the hearts and minds of medical residents to future specialists, the time to begin is in medical school.

In summary, I strongly urge that the comprehensive arthritis centers place major emphasis on training and research. Research is of importance not only for the development of new and improved methods of diagnosis and



treatment but for accurate assessment of presently available methods of care.

There is every reason to believe that in the years to come biochemical and immunological research and the industrious cultivation of the art of healing will yield an ever-more-bountiful harvest of knowledge leading to more effective treatment for the patient with rheumatic disease. Thank you.

ENGLEMAN: Thank you, Dr. Rodnan.

Dr. Rodnan did not mention his identification--that he is President of the American Rheumatism Association. We're delighted to have you here, Dr. Rodnan. Any question or comment? Yes.

SHIELDS: Dr. Rodnan, I picked up a Chicago Tribune, and I read an article that disturbed me somewhat, and I wondered if you'd respond to it. I read that the spokesman for the American College of Surgeons, Monday, called for a reduction in the number of new surgeons trained each year in our country. And my concern is that we're talking about the fact that we have a great need for doctors in one field, and yet, apparently in the surgical field, we have a need for fewer doctors. We could solve the problem easily by putting all these doctors into rheumatology, I suppose. Could you respond to why we have so many going in other directions and not into arthritis?

RODNAN: Well, the reasons for the choice of a specific subspecialty are many and varied. It is true that we believe that there are an excessive number of certain subspecialists in this country as compared to the figures from other countries throughout the world. There seems to be an excess of neurosurgeons in this country. The number of urologists is beginning to approach that which is more than adequate, apparently.

I think the situation is different, however, in most areas of internal medicine. While there has been some question about the need for a large number of additional cardiologists, I think all would agree that in the field of rheumatology we're still very far behind in meeting the demands for consultation service by rheumatologists.

As I said, there's no stated (inaudible) really close to the suggested figure of 5 rheumatologists for 100,000 individuals.

SHIELDS: Is it because of the reward system--that they're not rewarded monetarily? Is that one of the reasons, or just because of the chronic nature of the disease?

RODNAN: I imagine this is one reason. I think there are other challenges that draw people to subspecialties or other specialties other than rheumatology. But, here again, I point out that the time to start doing something about this is as early as possible. Rheumatology has to be more visible than it is at the present time in many schools. If it is visible, I'm sure that it will be able to compete very successfully for the attention of the medical students, interns and residents. But to do



that, one needs groups, one needs people who can do the teaching and do the planning of a program.

ENGLEMAN: Yes, Ms. Melich.

MELICH: I just wanted to make a comment on what you've been saying. Do you think that one of the reasons we have so many surgeons, as opposed to the few rheumatologists that we have, could be the fact that surgery is a very dramatic thing? They can see the cure of a patient right away, whereas in chronic diseases it's a long, dragged out affair.

RODNAN: Well, that used to be the image of rheumatology, not to say that the image is changing. Rheumatology is actually a very dramatic speciality. A lot depends on your definition of the scope of the field. But we have a number of diseases that are as fascinating as any that can be dealt with by the surgeons and where the changes and clinical solutions are just as dramatic.

Rheumatology, we must remember, is a very young subspecialty. It has only come of age within the past 20 to 30 years. And, only in the past 5 years has there been official recognition of the creation of a subspecialty Board of Rheumatology by the American Board of Internal Medicine.

I think that our growth rate has been good over the past few years, and we have a lot of catching up to do if we are going to meet up with the other speciality which has been around for a much longer period of time.

MELICH: We have to make it more visible.

ENGLEMAN: Yes.

OTCHIN: I'd like to ask you if you might comment on the way that rheumatologists are presently utilized within the larger health care delivery system? At some earlier meetings of this Commission and also our community programs work group there were some data discussed regarding a semirural community in northern California where the practitioners there seem to not really utilize rheumatologists or even admit to the need for rheumatology consultations in managing a fairly large number of individuals that, based on statistical analysis, would suggest a great need for rheumatologists.

Do you feel, in addition to the role that you're proposing for rheumatology centers, that this Commission should also recommend some very aggressive measures to improve the way in which the community physicians and the public at large look to rheumatologists for service?

RODNAN: I think that most certainly the Commission should include such things in its recommendations.

If you scan the list of postgraduate courses that appear in various medical journals, you'll see that rheumatology and its closely allied subspecialty [immunology] are extremely popular among physicians. There

are oodles and oodles of courses each year devoted to the field of rheumatology.

I think this represents an effort that one might call "catch up ball". Most physicians today, in fact, have had very little training--formal training--in rheumatology when they were in medical school. Thus, until relatively recent times most medical schools had very small programs of formal instruction. And then these physicians go out into the real world and discover that 1 out of every 10 people coming to see them comes because of a rheumatic complaint. Rheumatic diseases are extraordinarily common, as you know. They learn, then, that they have great need for instruction in the field of rheumatology, and so go to these--and subscribe very heavily to these postgraduate courses.

Those who feel that there is no need for the help of a rheumatologist may have gained enough knowledge from such postgraduate training to be able to take care of these diseases themselves.

I'm not for the moment suggesting that all people with rheumatic diseases have to be seen by rheumatologists. Fortunately, well-trained primary care physicians and internists can do a very fine job--that is, a great majority--with rheumatic disease. But I feel that some of these individuals who do not see the need for rheumatologists may not ever have been exposed to rheumatologists and may not ever have learned what a rheumatologist will do in order to help the individual. Too many physicians still maintain an overly pessimistic view about what can be done about the patient with arthritis.

ENGLEMAN: Yes.

SHARP: Dr. Rodnan, we have, with the Professional Education Committee of the Foundation, updated the report to which you referred and now it's complete. There are, in fact, now 19 institutions identified as having no rheumatic disease program, and 7 other institutions have a very limited program. So there are 26 institutions that really don't have much ability to have an impact on medical students and house staff and people that are going to be going out and caring for arthritic patients. I'd like to ask you, with this in mind, if you feel that the major reason for this lack of rheumatic disease units in these institutions relates to the lack of manpower of appropriate academic people? If so, is our first priority, perhaps, to try to create this critical mass of educators to staff these institutions?

RODNAN: I think there's no question that there's an enormous demand, an enormous unmet demand, for well-trained rheumatologists both for academic and clinical positions. Even before becoming President of the American Rheumatism Association, I received many requests for help in locating such individuals from centers in other parts of the country.

We, ourselves, at the University of Pittsburgh, have been looking desperately during the past year for additional personnel. It's very difficult to find an unattached rheumatologist these days. Everyone is looking for additional manpower. This is probably one of the chief

reasons why there are now, as you say, 19 institutions in this country which have been unable to mount a rheumatology program.

ENGLEMAN: Dr. Polley.

POLLEY: I'd like to say that I haven't seen Dr. Sharp's data, but I think we should all recognize that, of those medical schools that do have adequate programs, a great majority of them have been staffed by NIH training programs, and we shouldn't overlook a positive correlation.

ENGLEMAN: Yes, Dr. Whedon.

WHEDON: NIH training programs--as Dr. Polley mentioned, I would assume that you have in mind, Dr. Rodnan, that such programs ought to be either resuscitated or revived over their current state. In doing so, is it your view that providing mainly fellowship support is adequate? Or, to put it another way, to what extent, if any, do institutions or divisions of rheumatology need support above the modern day rheumatology training grants for the environment of the training for the fellow?

RODNAN: I would endorse the statements that have been made in saying the role of the National Institutes of Health (inaudible) in the field of rheumatology. There's no question at all that the enormous growth and development of the field is related in large measure to the support given to training programs throughout the country during the late 1950's and throughout the '60's, and even up to the present day.

I think the greatest single need for support at the present time is that for fellowships. I would agree with Dr. Whedon's suggestion in this regard. It is a very difficult matter to obtain these funds. There are very few hospitals which have taken what I consider to be the enlightened position of supporting such goals.

Our own institution, fortunately, the Presbyterian University Hospital, does this in Pittsburgh. But it's becoming increasingly difficult, year by year, to find an adequate amount of funds in view of the galloping inflation that we all labor under. Fellows today receive a beginning salary which is in excess of twice what faculty members received not too many years ago. It is becoming more and more difficult to obtain adequate funds to support a growing group of clinical and research fellows. I think that some support of faculty trainers is desirable. But I would agree that it is chiefly the role of the university itself to take care of the bulk of this expense.

ENGLEMAN: Thank you very much, Dr. Rodnan. We'll now call on Dr. Bachman.



TESTIMONY OF  
LEONARD BACHMAN, M.D.  
HEALTH SERVICES DIRECTOR TO GOVERNOR MILTON SCHAPP  
SECRETARY, PENNSYLVANIA DEPARTMENT OF HEALTH

BACHMAN: Thank you, Mr. Chairman and members of the Commission.

I'm Dr. Leonard Bachman. I serve as Health Services Director to Pennsylvania Governor Milton Schapp, and as Secretary of the Pennsylvania Department of Health. I'm here today representing over a million Pennsylvanians who are now victims of arthritis and those in the future who will face this disease.

National figures on the death of individuals and the breakdown of family units are staggering. Fifty million Americans have arthritis. Twenty million have it so severely they need medical care. Arthritis strikes both young and old in one out of four families. Women are affected twice as often as men. Arthritis claims 250,000 new victims per year. This disease is a killer and the Nation's number one crippling disease. I suppose that's no news to you members of the Commission.

Here in Pennsylvania we have only estimates, at this time, of the total number of our citizens who are affected by this disease, but we know the numbers are significant and they are increasing. Here in central Pennsylvania, for example, in a 23-county area, with a population of 2.3 million, there are an estimated 223,519 victims of arthritis.

A disease which causes disablement of 3,500,000 Americans, a disease which causes them to lose 3.5 billion a year in wages, a disease which costs victims 2.5 billion in medical costs annually deserves a closer look by government, by health professionals, and by the medical profession itself.

Here in Pennsylvania we are beginning to take a closer look at arthritis. I am pleased to be able to announce today that Pennsylvania Governor Milton Schapp has agreed to appoint a special governor's task force on arthritis within the very near future to look into this crippling disease in our state. What concerns Governor Schapp and myself, however, is that we have a concrete and practical mission that this special task force can assume. A paper task force, no matter how worthy its intentions, will accomplish little or nothing to alleviate the pain and suffering of the victims of arthritis.

It is not enough that President Ford signed the National Arthritis Act into law earlier this year. Thus far, funds have been appropriated only for the operation of the Commission itself. Nothing has been done to free funds which would implement new programs in research, health education, communications, training, and treatment.

It is not enough even that we throw even more billions of dollars and resources into our already massive health care machine, which this year we'll spend about \$120 billion, some \$17 billion more than they spent the year before. Not that we doubt that this machine could not absorb an infinite quantity of dollars, but we do have genuine doubts as to whether

we would really advance the cause of victims of arthritis not in our lifetime or in our children's lifetime. The turning on of the money tap without knowing where the resources will directly flow or how much good they will do would be disastrous.

A pain-racked victim of arthritis in 1975 wants something other than a couple of aspirins and a warm bath. And as I listen to the testimony of the specialists in rheumatology, and admitting that there have been many advances, as I can look back to my medical school days, 30 years ago, the victim of arthritis today seems to me to be not much better off than his counterpart who struggled with this disease in the Middle Ages.

Even today, with our advanced medical technology, victims of arthritis are spending \$400 million a year on worthless cures and remedies, quackery that has its roots in medieval days. While I'm on the subject of quackery, let me share with you a sample of a product that the Pennsylvania Department of Health's Drug, Device and Cosmetic Section has been clamping down hard on, the copper bracelet. And I won't read to you everything that's said here, but it's presented as a short cure for arthritis, tennis elbow, and anything else.

Earlier this month the Pennsylvania Department of Health closed down a Philadelphia drug firm with a history of repeated violations of state laws and regulations relating to sound manufacturing practices. The firm in question, the Cabasil Company, whose product I hold here--and I didn't bring the product, but it was an arthritis cure--had been cited repeatedly in the past for a variety of violations, including inadequate records, lack of testing procedures and facilities, poor sanitation and storage, and deceptive labeling. These tablets, I might add, indicate on their label the following quote: "Aids in the relieving of some of the symptoms associated with arthritis." Eliminating quack products on the market is only one answer. It, in itself, is not enough. We must begin now to confront the total problem.

The governor's task force on arthritis, it is hoped, will bring an all-out effort to determine answers to such questions as:

- (1) How can we better help to educate the consumer and the medical profession to the unique problems of the victims of arthritis?
- (2) How can we encourage the schooling and training of rheumatologists?
- (3) How can we exert pressure on the medical profession to update and continue their education in the discovery and treatment of arthritis? This alone would prevent millions of unsuspecting arthritis victims from going undiagnosed and untreated for long periods. This latter condition unfortunately results all too often in permanent and irreversible damage to unsuspecting victims.
- (4) How can we best set up community-based screening programs to discover and begin treating people with this disease?

- (5) How can we fund the care of victims who do not have the wherewithal to obtain private treatment?
- (6) How can we end for all time the unscrupulous practice of some merchandisers who bilk arthritis victims of their lifetime savings on quack instant cures?
- (7) How can we best coordinate this with the Commission and other agencies on the state and Federal levels?

These are but a few of the questions with which the Pennsylvania task force on arthritis must immediately address itself to once the committee is formed.

As I say, these are the questions. We must find the answers. And I'm an optimist who believes that we can find the answers, and we can improve the lot of those of our citizens who suffer from arthritis if we have the will.

ENGLEMAN: Thank you very much, Dr. Bachman. And on behalf of the Commission, I want to extend our congratulations to you and to the Governor on your decision to fund a task force on arthritis for the State of Pennsylvania. When you get the answers to all these questions, and they're certainly vital questions, what do you see as the role of the state in attempting to implement the answers?

BACHMAN: Well, we have taken the position in this administration that the state is a critical missing factor in the health care equation in our country. Under the Constitution of the United States, the states have the primary role to promote and protect the public health. In general, this role has been a very passive role in the last 25 years. And I think some of the problems in the health care system today are a result of the failure of the states to live up to their responsibilities in the health field, and those responsibilities are these:

First, to plan a health delivery system in each state, and in our state, that has the components that the citizens need, and that brings the Federal aims and goals and the national policy on health into the state health delivery system. The state is responsible for bringing the interests together within any given state to plan the health delivery system. It is also responsible for deciding how the resources should be used in a given state.

We spent \$6 billion in Pennsylvania. In my judgment, if we spend \$6 billion, there's enough money in that to take care of those people that have arthritis if we're willing to exact the kind of priority decisions, on a state level, that have to be made.

The state is responsible for educating the health professionals within its confines. We spend, in Pennsylvania, \$21 million alone as direct subsidies to medical schools, besides the fact that we educate most of the nurses and most of the other professionals who are directly educated by state programs. We have a responsibility, therefore, to see that the professionals that we educate meet the needs that the people have. And,



certainly, arthritis care is one of the needs that people have. These statistics demonstrate that. So we have and should have tremendous influence on what medical schools teach, and we're going to have more influence in the future.

The second area that the state has a major responsibility in is the quality of care that patients receive in the health delivery system. We license the physicians of the state; we license nurses and a variety of other health professionals; we license hospitals; and we license nursing homes. Therefore, we have the responsibility to the individual citizen to ensure that the facilities and services that he confronts meet quality standards. In that way the state can have a tremendous impact on improving the lot of arthritis sufferers.

The state is a major cost of health care. The state has a responsibility and--probably the only agency that has the wherewithal--to really control the cost and inflation in health care.

In Pennsylvania, hospital costs this year are going to go up 20 percent--something like three times the inflation in the rest of our economy. Now, with our citizens putting that kind of money just into hospital care, to just more or less walk a treadmill in hospital care, we're not going to free up new resources to put into programs for arthritis.

The American people have decided that they've spent enough on health care. It is already 8 or 9 percent of the gross national product. As I told you, it'll hit \$120 billion a year. The American people don't want to put any more money than that into health care. But they want us to spend the money differently. They want us to change our resources. And, certainly, arthritis is an area that we ought to put more resources into. That means taking it away from some of the present interests that have that money. That means upsetting vested interests. I don't think this Commission should feel that it's going to make any real reforms unless it's willing to take on, in its report and in its recommendation, the vested interests in the health care field. Sorry to make that speech.

ENGLEMAN: You want to name one or two of those vested interests?

BACHMAN: Well, you mentioned surgeons. I'm an anesthesiologist. I know a lot about surgeons; they're wonderful people. But somebody asked why there were so many surgeons in this country. Well, it's simple. They make more money for less work than all the rest of the physicians, and so there's more of them. This has been true for the last 30 years, and surgeons and physicians are no different than anybody else.

ENGLEMAN: Yes.

SHARP: Dr. Bachman, I wonder if I could ask just what it was that persuaded the Governor of Pennsylvania to establish a task force on arthritis? Who will be some of the representatives, the types of people on such a task force? And how will this ever be supported?

BACHMAN: I'm pleased to answer that. First of all, we have found that the development of a limited task force is a very good way for us to solve problems in Pennsylvania. We have a main Governor's Health Task Force, which was established as soon as the governor got into office.

We had a crisis in Blue Cross rates, and because of that we began to understand that the state's role in health was massive. And we established a Governor's Health Task Force with subcommittees in various areas; for example, emergency health care, sickle cell anemia, infant care--we have a very high mortality rate in Pennsylvania which we're not very proud of. In a number of different areas like that we have established task forces. They have published reports, which then become the basis for our policy in a dozen areas. About a year ago, the members, people in Pennsylvania who were--I believe Dr. Sussman, right here, from this community, came into my office, and he began to expose to me the problems of arthritis. And it became clear to me--which, by the way, we do have a task force on--diabetes. It started as a task force, and ended up as the Pennsylvania Diabetes Institute, diabetes being another massive public health problem.

He saw what we had done in diabetes, and visited me, and exposed me for the first time to this massive public problem, for which the statistics were, it seemed to me, overwhelming. And I promised him at that time to give serious consideration to establishing a governor's task force to try to put together what Pennsylvania could do. Your coming here and having your hearings here is an immediate stimulus to living up to that commitment that we made to Dr. Sussman about a year ago.

The members of it will be as broad a representation as possible. We like to keep them from getting too numerous. I've found that somewhere between 12 and 20 is a good number. It will not be solely academic professors of rheumatology, although we'll have one or two of them. We'll probably get the various interest groups, like organized labor, other consumer groups, in there--the groups in our society that have clout and power and make decisions--so that they can understand and be part of the task force. And we will try to get some ordinary citizens with an interest and volunteer people to represent volunteer organizations, the Arthritis Foundation people in our state. We've found that type of representation to be very valuable. They're advocates for the problem. Those are the kinds of people who will be represented.

SHARP: How will this be supported?

BACHMAN: The financial support will come from the funds of the Health Department, and we, frankly, do not fund these things very heavily. We provide traveling expenses, and we provide usually one part of a staff person, a couple of staff people from our Health Department to take the minutes, and to take care to see that the expense vouchers are paid and things of that nature, and finally to do the printing.

One of the things that I've found since I've had this job, is that citizens of the United States--and I guess of Pennsylvania, and I'm sure it must be true of other states--are immensely willing to contribute their time and effort if they think something good is going to come out.

Pennsylvania is a state of 11 1/2 million people, and we have some of the best brains in the United States right here. We have found that those kinds of people do come to meetings and they give of their time, energy and effort unstintingly. So we don't lock to this to be any high-cost operation; \$5 or \$10,000 is going to do it.

ENGLEMAN: Dr. Bachman, your funding system is at least as good as that of our Federal government in terms of the Commission's report. Thank you very much, Dr. Bachman.

TESTIMONY OF  
ALLAN MYERS, M.D.  
DIRECTOR, DIVISION OF RHEUMATOLOGY  
UNIVERSITY PENNSYLVANIA

MYERS: Let me begin by introducing myself. I'm Al Myers. I'm the Director of the Division of Rheumatology at the University of Pennsylvania; and in line with Dr. Rodnan's, Dr. Whedon's and Dr. Polley's comments, I was a recipient of support as a trainee for an NIAMMD grant, a training grant to the Massachusetts General Hospital when I was a fellow there.

Mr. Chairman, members of the Commission:

Thank you for allowing me to appear before you in order to give my personal views concerning the proposed role of arthritis centers. First and foremost, I believe that they should be centers of excellence dedicated to research, education, and patient care. In regard to research, investigations must be carried out at a basic science and clinical level. Broad areas should include immunology, molecular biology, connective tissue, biochemistry, genetics, physiology, and bioengineering.

By necessity, the research must have an interdisciplinary flavor. Nowhere is this more obvious than in a study of articular cartilage; for example, where conventional medical sciences, such as biochemistry and physiology, are augmented by disciplines such as biomechanics, biophysics and biomaterials. Clinical research requires a similar approach if we are to understand the causes and expressions of the disease entities we deal with and attempt to modify or even cure them by various treatment programs.

In regard to education, strong teaching programs are necessary to encompass medical students, house officers, practicing physicians and paramedical personnel. In view of the national trend to increase the number and caliber of primary care physicians, it behooves us to train these physicians well during their formative years. After all, specialists do not see the patients initially, so the primary care physician must be able to diagnose and manage general rheumatic disease problems and recognize when to refer the more complex patients to the rheumatologist.



In addition, more rheumatologists are necessary so that communities can have the availability of expert advice in this area. Our own state apparently suffers in that regard.

Programs designed for the practicing physician must be evolved, whether it involves reaching out to him by telephonic instruction or audio-visual teaching programs or postgraduate courses or bringing him into the university for refresher courses. Paramedical personnel also need strong primary education and postgraduate programs.

In regard to patient care, we must relate the fruits of research to the care of patients. Again, a multidisciplinary or team approach involving rheumatologists, orthopedic surgeons, physiatrists, engineers, dentists, occupational and physical therapists, specially trained nurses and social workers is vital.

If we can agree on the principal functions of an arthritis center, the next step to consider is: What might be the organizational structure? From my standpoint, while it must be interdisciplinary, it also must be a manageable entity. For if it is too large, the risks of waste and inefficiency exist. The institutions chosen for centers should have a record for previous commitment and accomplishment in all of the functions--that is, research, training, and patient care--so that support is not given for only a promise.

They must demonstrate a coordinated environment where scientists, clinicians, and teachers communicate freely. Those institutions should have an established, identifiable patient population so that continuous epidemiologic and clinical data may be accumulated by knowledgeable students of disease. Realistically, clinical research can best be done in institutions where ideas and technical know-how flourish.

Why is support needed, then, for institutions with ongoing programs? Because today, when we need the flexibility to respond to multiple challenges, research funding is severely limited, funds for educational purposes often must be siphoned from other areas, and patient care activities are often overwhelming in our limited status.

In conclusion, the establishment of arthritis centers is an ambitious and vitally necessary program. The purpose of the centers should be carefully weighed lest their charge be too broad and their chances for success too slim. Thank you.

ENGLEMAN: Thank you, Dr. Myers. Any questions?

(No response.)

ENGLEMAN: Are you proposing an all-inclusive type of center? I mean, you've covered the waterfront.

MYERS: Yes, sir.

ENGLEMAN: And you think that these centers should make possible all of these functions that you've just suggested?

MYERS: Yes, I do.

ENGLEMAN: This is slightly in contrast to the testimony we heard earlier from Dr. Shulman who thought that perhaps the centers might be a little more selective.

MYERS: I think the example for this, Dr. Engleman, is really the charge of the centers established by the Arthritis Foundation. They are really asked to perform in all areas; that is, research, teaching, and patient care.

ENGLEMAN: Dr. Whedon?

WHEDON: On the other hand, if I understood you correctly, you urged twice in your statement that the centers' activities not be too broad. What did you mean by that?

MYERS: Yes, sir. I think that there are certain activities defined in the legislation which I would like to defer from the centers, particularly those outreach programs which I feel, as Dr. Tourtellotte and Mr. Salmon mentioned, use tremendous time of the personnel of university centers. Also, screening and detection programs may be best carried out by other groups, perhaps through the Arthritis Foundation. And public education, I think, is a primary job of the Arthritis Foundation, for example, if one uses the American Cancer Society or the American Heart Association as examples in that line.

ENGLEMAN: Any other comment, question?

(No response.)

ENGLEMAN: Thank you very much, Dr. Myers--oh, sorry. Did you want to say something?

DONALDSON: Yes. I'd just like to ask you what your opinion is concerning the role of continuing education for the practicing physician as it relates to the delivery of services and improved quality of delivery of services?

MYERS: Yes. I believe that the university can serve a very important function in this area. I think that we can develop programs, particularly in areas, for example, of televised instruction to outlying hospitals that are a considerable distance away from the university centers. I think that we have devised a number of audio-visual programs for practicing physicians to use. And we have also brought physicians into our clinics to update their competence in this area. For example, cancer centers now are asking practicing physicians, which is support, to come in for periods of time, and I think this would be a valuable approach.

SHARP: I'd like to ask a question Dr. Engleman asked an earlier speaker. Would you have 10 centers or 40 centers? Secondly, if you defer outreach, screening and detection, and public education, by what mechanisms will those activities be carried out in the broad picture?

MYERS: Let me answer the second part first. I think, as many speakers have alluded to today, particularly some of the lay speakers, the answer to our problem is, I think, in crude research--to develop the modalities to diagnose and to understand the cause of these diseases. And if we can do that, I think that the rest will follow reasonably easily, as exemplified by the infectious diseases, in terms of poliomyelitis, and so forth.

In regard to who might do those activities, I think that examples of institutions that may do them are, for example, the Arthritis Foundation. Again, if you remember what I said before, the American Heart Association and the American Cancer Society are very effective at public education and screening programs.

To answer your really tough question that you posed, and Dr. Engleman posed before, how many centers. Well, that depends upon how much money you have. If not 40, then maybe 20.

ENGLEMAN: Thank you very much, Dr. Myers. Mr. Donsen.

TESTIMONY OF  
CHARLES B. DONSEN  
PRESIDENT, ARTHRITIS FRIENDSHIP CLUB  
CENTRAL PENNSYLVANIA CHAPTER, ARTHRITIS FOUNDATION

DONSEN: Good morning, ladies and gentlemen.

I am Charles P. Donsen of Hanover, Pennsylvania. I'm President of the Arthritis Friendship Club sponsored by the Central Pennsylvania Committee.

I'd like to take a few moments to give you a few particulars of my own experience with arthritis. While serving in the U.S. Navy in 1944, I had my first encounter with the disease. I had a terrifically high fever for no particular reason at all. I might add that the Navy doctors didn't know what it was, so, typically, they called it "Cat Fever". You've probably run into that term before.

Anyhow, I had a few flare-ups in the next 11 years. In 1957 I spent about 6 months as a patient at the Veterans Hospital in Lebanon, Pennsylvania. Since then I have been working almost every day and keeping as active as possible. There, I'm active in many things, going to the movies, and secretary of a fire company. And so I think I'm keeping myself active, which, in my own opinion, is the secret to getting along with this thing.

I have been giving the subject of arthritis a lot of thought since I have been asked to testify, and I am convinced that the first thing that should be done is to expand and speed up medical research programs. I know the Arthritis Foundation and affiliated organizations have been spending millions of dollars on research. But I think that if more money and more time were put into research to hire more technicians and research people, I feel confident that a cure for arthritis could be found in a reasonable length of time.



Second, I think that more clinics and rehabilitation centers should be set up for the treatment of arthritis. A large number of people in the lower income brackets cannot afford the expensive treatment and rehabilitation provided by private institutions. I know, in my own case, that had I not been a veteran of World War II, I could not have afforded the treatment I received at the Veterans Hospital in Lebanon.

I think these clinics should be set up on what-you-can-afford-you-pay basis, or possibly a Federal-Government-sponsored clinic could be achieved. These clinics should be provided so that arthritics do not have to travel 50 or 60 miles for treatment. I know, in my own case, the nearest rheumatologist is in York, Pennsylvania, 20 miles from my home.

In conclusion, I would like to stress that I think research is the answer. If given the time and effort, I think the disease of arthritis can be cured. Thank you.

ENGLEMAN: Thank you very much, Mr. Donsen. Any comment or questions?

(No response.)

ENGLEMAN: Congratulations on the way you handled your "disability".

DONSEN: Well, the doctor told me at Lebanon years ago that mental attitude is the basis of whether you're going to get better or worse. He said, "You'll make out all right. You're a stubborn Dutchman." So I guess I've been making out all right.

ENGLEMAN: Very good. We'll now call on Dr. John Decker.

TESTIMONY OF  
JOHN DECKER, M.D.  
CHIEF, ARTHRITIS AND RHEUMATISM BRANCH, NIAMDD

DECKER: Dr. Engleman, and ladies and gentlemen of the Commission:

I'm John Decker, and I'm Chief of the Arthritis and Rheumatism Branch of the National Institute of Arthritis, Metabolism, and Digestive Diseases in Bethesda, Maryland.

I have chosen to talk about arthritis. At least I thought I had chosen. Listening to my confreres today, I get the impression I might have been led in that direction.

But in any event, I do believe that it is a very important matter which the National Arthritis Act deals with, sort of out-guessing this Commission in the sense of recommending these comprehensive arthritis centers right off the bat, and then it says later that "they shall be consistent with the plans of the Commission," subsequently so. I was interested in that, and I feel that it's a matter very much worth discussing. My views on it will be of a very personal nature.

I've had experience as the leader of a university arthritis unit. I've had some experience in the intramural program of the National Institutes of Health, and recently some time in the Nuffield Orthopedic Center in Oxford, and these would be my contributing background factors, I suppose. I did review and reconsider the center concept as a member of the organizing committee and of the resulting conference on arthritis centers, which took place last spring, the spring of '74, in Chicago.

I would be inclined to define a center as, essentially, a group of people banding together in order to serve arthritis patients with every tool at their conjoint command--a group of people. This definition deliberately emphasizes the fact that it is the arthritis patient around whom the concept of center arises. Medical writings are full of the need for a combined multidisciplinary approach to the often complex problems involved, and I will not belabor the point. I consider it well taken. One rarely follows a patient with chronic musculoskeletal disease over a 1 year period without feeling the need for assistance, advice, or, at the very least, discussion on the situation at one or many points. The professional backgrounds of those to whom one turns on such occasions cover a huge spectrum, and, again, need not be belabored, except to say that the value of the ideas put forward in reference to any specific patient seems rather poorly, if at all, correlated to the number of academic degrees held by the advisor. This advice comes from a wide spectrum of experienced people.

Considering a center to be "a group of people," one must be certain that the members of the group have a chance to interact and communicate in the course of actually rendering the care involved. That statement, it seems to me, could be thought of as limiting the size of a center program to a group of people who can, in practice, communicate with each other. Written consultation requests and reports are very desirable features of medical records, but, in real life, face-to-face encounters are the most effective in decision making.

The "clinic conference"--you could call it the "center conference," I suppose--is a key element in decision making and arthritis center building. From it can come brisk arguments, new ideas, new study proposals, revised plans for one station, and an esprit which can involve everyone from patient to doctor, from clinic clerk to consultant radiologist in the work of the center.

I view the "clinic conference", too, as a key element in the training program of the center. Here learners at many levels can present their findings of the patients and have them checked and discussed. More advanced learners can enter into discussions of abstruse findings or indications. Listeners can readily learn the elements upon which decisions are based.

Above all, the "clinic conference" can be a key element in the records of an arthritis center. Given a few points to be regularly recorded in the conference book, one can end up with a year's records which provide a remarkable description of the actual performance of the clinic, all without the use of a computer. This can be elaborated in any way desired

with emphasis on intake status, on discharge status, or on status of one year.

The "clinic conference" is also a useful arena in which to discuss and review protocols for arthritis center research projects; although, in most cases, the required maneuvers and observations will not be carried forward in the conference itself. The kinds of questions that arise at clinic conferences and the modalities of observations to be used in answering them are very much at the heart of the entire national task of alleviating the scourges of the several diseases involved. This type of research, some of it mundane and not necessarily exciting, some of it slow to yield results, and most of it producing virtually imperceptible advances in improved patient care, is usually stimulated by the clinic conference, and can only be carried out by a doctor and a patient together working on a predefined plan.

To me, the most important feature of the entire arthritis center concept is its encouragement of research questions and research methods brought directly into the care situation. Modern trial methodology, which permits the assessment of two or more modes of management randomly assigned to cooperating patients with a view to distinguishing the one to be deferred, this kind of thinking, this kind of patient examination and evaluation, this kind of work, to me, constitute the *raison d'être* of the arthritis center and are freighted with enormous possibilities for the future. It is just this situation that constitutes the famous three-legged stool: patient care, research, and teaching, all carried forward together, and each weakened by the absence of any other of the triumvirate.

I view exogenous support of the arthritis center--that is, support that's got to come in from the outside rather than that which would be patient or third party generated within the center--I view this exogenous support as paying for the required time to develop such research projects, the time to exercise the imagination necessary, and the time to do the required reading. In some instances, the funds should also cover some of the clinic expenses of the patients; since, often, protocols will require a more comprehensive assessment of a patient than could be justified by the best current medical practice. Some protocols will require time in hospital, and the center facility should include a few beds which could be so used at no cost to the patient or his third-party insurer.

It seems to me perfectly proper that the center's capacity for training not be confined to research training. I am of the view--and this is obvious--that the Nation is in need of persons with the requisite skills for the delivery of first quality care, and that the training of such individuals, whether or not they expect ultimately to engage in investigational medicine, is an important center function. I am not with these words addressing the problem of financial support while in training, a most important issue, but only the regrettable concept that the production of people who elect to work in patient service only is, in any degree at all, improper or representative of a failure in a larger context.



While it is impossible to predict the shape of the ultimate conquest of the disease that is called rheumatic, it is reasonable to suppose that the most fruitful approaches will be through the increasingly exact sciences of immunology, biochemistry, virology, and the like. In my view, a balanced arthritis center would require expertise in one or more of these areas. The disease-related thinking of investigators in these fields would surely be enhanced and strengthened by the stimulus of the patient care setting. The presence of such fundamental biological thinking would also result in the development of the important persons capable of erecting and testing the conceptual bridges or hypotheses which span the gap from test tube to patient. My own personal bias toward investigative medicine earlier emphasized is not meant to denigrate more fundamental approaches. The two work in different time frames, but both will ultimately serve the patient and neither should be excluded.

A final point: surely it is clear that the proposed centers, as here visualized, are models only and could not be expected to care for even a small proportion of Americans with arthritis. Nevertheless, the concepts, and those that more center work will produce, can be expected eventually to contribute to better care for every arthritic.

I am sure, Mr. Chairman, that the same can be said of the work of this Commission.

ENGLEMAN: Thank you very much. I wonder if there are any comments, questions from the members of the Commission? Yes.

OTCHIN: DR. Decker, I wonder if you might comment on what percentage of patients that might attend an average academic rheumatology care program would benefit or should require the sort of center conference regimen that you propose? Do you think a large number of people really are getting substandard care because of the kind of ad hoc communications that now may take place, or do you think that this is needed for almost everybody?

DECKER: Dr. Austen, I suppose that (inaudible) care develop in any unit, and there are ways in which one can go down the pattern trail without having to discuss it with anybody. On the other hand, I would guess that a properly organized clinic conference would affect the care of as many as half of the patients seen in that clinic--not necessarily for the better, mind you; some conferences can come up with ridiculous suggestions. But it's important that these things be brought out on the table and discussed for the training purposes of which I am speaking.

ENGLEMAN: You made no reference to the concept of the outreach programs, Dr. Decker. Do you have any gut feeling about this? How effective do you think it would be as a function of the center?

DECKER: I really was--you're right, Dr. Engleman--thinking of sort of in-house materials and conferences. I tend to be fairly optimistic about the outreach aspects. I believe that one of the most important elements of this center thing is communicating with those around you. I would like to see those working in rheumatology join in the work of the center. I would like to see people from the center using satellite clinics. And I

believe that the whole can--indeed, I think it must--be integrated, although I am also aware that this causes some pain among those whose only concerns, let us say, are the different medicines prescribed. I think that we have to go that distance at least.

ENGLEMAN: Any other questions?

DECKER: I think our biggest problem with this whole idea, sir, is going to be in estimate of quality of centers. This is what worries me. When you actually come down to supporting a program, how are you going to make the decisions that this program in state Y will be of a lower priority than that program in state X? And these are matters of--that you would like to support the testing of these centers. How you're going to make those decisions, I find that an extremely difficult question.

SHIELDS: Dr. Engleman?

ENGLEMAN: Yes.

SHIELDS: One question regarding the feeling of what type of manpower is needed. What should that center group be made up of?

DECKER: I don't want to make a statement about that because I'd rather leave it open. I can imagine that, let's say, four orthopedic surgeons could set up the kind of center that I have in mind with nobody assisting them.

I'm not categorizing. I don't think that would happen. And my view is that you would have the many disciplines represented in proportion to the need as it arose; that is, presumably the ophthalmologist would be a consultant, whereas the podiatrist and orthopedic surgeon, and perhaps pediatrician, would be (inaudible).

SHIELDS: You mentioned all physicians in this regard. What are your feelings regarding the allied health people as members--active, participating members of this?

DECKER: I didn't refer to allied. Well, I'm very sorry, Mr. Shields, if I did that because it's totally incorrect. My allusion to saying that I often got good advice which wasn't very well correlated with the number of academic degrees was very much meant to include the fact that I consider the physiotherapists, nurses, all of the allied health profession's own key people very much a part of the center. I can't imagine trying to perform in this area today without that sort of active involvement, not just support, but in it, too, with their own research ideas.

ENGLEMAN: Thank you, Dr. Decker. We'll now call on Mr. Robert Richardson.

SUBMITTED STATEMENT OF  
ROBERT W. RICHARDSON  
WESTERN PENNSYLVANIA ARTHRITIS PROJECT  
St. MARK MEMORIAL HOSPITAL  
UNIVERSITY OF PITTSBURGH SCHOOL OF HEALTH-RELATED PROFESSIONS

RICHARDSON: I represent the Western Pennsylvania Arthritis Project, St. Margaret Memorial Hospital and the University of Pittsburgh, School of Health Related Professions. Appendics I, II and III briefly describe their activities in arthritis care.

I believe our experiences have direct and important bearing on the future of arthritis care programs and services. My testimony is drawn from experiences made possible by these programs.

We have placed special emphasis on a system of diagnostic, therapeutic and rehabilitative services throughout the western Pennsylvania region utilizing existing personnel and resources. Services and programs are aimed at increasing awareness of all who are affected by arthritis--patients, doctors, allied health professionals and the community in general.

The prime ingredient in the Regional Medical Program (RMP) Arthritis Project is our multidisciplinary approach which includes at least the following professionals--coordinator, orthopedic physician, medical physician, nurse, physical therapist, occupational therapist, social worker and vocational counselor. We believe the diversity of disciplines ensures that the complexities of medical, psychosocial and vocational problems which accompany arthritis are met as fully as possible. To date, four regional arthritis facilities have been organized in communities outside Allegheny County where none were previously available.

Rapport was established with these outreach facilities by initial interviews conducted with the staff. These meetings discussed program objectives and determined gaps in their proposed care plans. These gaps became the goals for subsequent orientation and training courses for each facility's staff.

The four deficiencies most commonly cited were:

- (1) Basic lack of knowledge of current practices in evaluating and treating the arthritis patient.
- (2) A multidisciplinary approach is generally not used.
- (3) Little communication exists among various health care disciplines.
- (4) Lack of awareness and use of available community resources.

In conjunction with the University of Pittsburgh, several approaches to continuing education are being taken. Short-term training programs have been developed to train more practitioners with new skills in arthritis care. Now, we are working on self-instruction materials



(Appendix IV) for professionals in the outreach facilities and underserved areas. These materials incorporate such techniques as programmed texts and other self-instructional materials. This approach has wide application.

A coordinated multidisciplinary approach requires an integrated community effort. Our definition of an arthritis care center is more that of a consortia, or team, composed of institutions, their individual and joint programs and personnel. The University of Pittsburgh with its vast health resources provides a sound foundation in basic education and research. St. Margaret Memorial Hospital, an affiliated patient care center, provides a base of clinical education and research and the opportunity to develop and test patient care techniques and approaches. Our outreach facilities organize and coordinate existing care resources--people, facilities, services--to provide screening and comprehensive care.

In summary, the arthritis center, or consortia, must be responsive to the arthritis patient's total needs, medical, emotional, social and vocational, channeling patients to the comprehensive care required.

The approach I have described means trained, and fully utilized, teams of professionals. I believe the most urgent requirement under the new arthritis act is for support of educational activities:

- (1) Graduate Education--to train more professionals in the care of patients with arthritis--teachers, researchers and clinical specialists.
- (2) Continuing Education--to improve and build skills and knowledge of techniques, methods and approaches. An enormous need exists for personnel presently working with arthritis patients.
- (3) Patient Education--inclusion of the patient in the decision-making process of treatment and care is fundamental. If the patient is to be actively involved, more patient education programs must be offered.

The role of the allied health professional in the care of the arthritis patient must be more broadly and specifically defined. In most cases, they are not utilized to the extent possible. Their potential contribution to patient education, patient care and community planning is enormous. Furthermore, funds must be appropriated to develop more and better model centers with the goal of truly meeting the needs of patients with arthritis by way of progressive programs, clinical research, data collection and analysis.

Lastly, and I quote Mr. Martin's written testimony, "The public, just as health practitioners, should be educated to the latest medical advances and sources of care. The public needs to know about arthritis, all aspects of arthritis".

Robert W. Richardson  
Pittsburgh, Pennsylvania

APPENDIX I

The Western Pennsylvania Arthritis Project was developed by St. Margaret Memorial Hospital in cooperation with the University of Pittsburgh, School of Health Professions and the Western Pennsylvania Chapter of the Arthritis Foundation. This project, sponsored by the Western Pennsylvania Regional Medical Program with a grant from the Department of Health, Education and Welfare has been operational since June, 1974.

The purpose of the project is to develop and implement a coordinated network of regional or outreach facilities in western Pennsylvania that would enhance the delivery of care to arthritis patients and provide educational and consultative services for physicians and health care professionals of that region. During the first year of the project, five area institutions participated in the development of a network of services while short-term training programs and consultative services were provided for professional staff from these facilities.

Projected activities for the second year include:

- (1) Development of two additional regional facilities with continued training and consultative services and;
- (2) Conversion of the educational activities into self-instructional packages. With the major emphasis on development of these self-instructional packages, the project hopes to increase the availability and accessibility of specialized education for health professionals caring for patients with arthritis.

Robert W. Richardson  
Pittsburgh, Pennsylvania

## APPENDIX II

St. Margaret Memorial Hospital is a 250-bed general community hospital that provides a wide range of acute care services including medicine, surgery, obstetrics and pediatrics. In addition, the hospital supports a regional referral center for the treatment of arthritis and related chronic diseases with a complementary program in medical education and clinical research.

The rheumatology program is one of the largest of its type in Pennsylvania. Of the 14 rheumatologists in western Pennsylvania, 9 are active admitting members of the St. Margaret Memorial Hospital medical staff.

Through the years, the rheumatology program has grown into a regional referral center for patients with arthritis and related chronic diseases for western Pennsylvania and the tri-state area. Continued increases in the volume of rheumatology patients and patients who required orthopedic surgery led to the coordinated program of care.

The Department of Comprehensive Medicine and Rehabilitation was developed to provide a system of care for rheumatology and orthopedic patients based on the multidisciplinary approach. Health professionals involved in this team approach include rheumatologists, orthopedists, nurses, physical therapists, occupational therapists, audiologists and speech therapists, social workers and vocational counselors. The Rehabilitation Nursing Unit consists of a centralized inpatient complement of beds and nursing service personnel who specialize in rehabilitative care for arthritis patients.



APPENDIX IIIEDUCATION OF ALLIED HEALTH PERSONNEL IN THE  
CARE AND MANAGEMENT OF ARTHRITIS AND  
RELATED MUSCULOSKELETAL DISEASESIntroduction

Allied health personnel are naturally and extensively involved in the care and management of arthritic and related rheumatic diseases. They provide a valuable and effective source of medical input directly to the patient suffering from the varied affects of arthritis. The role of the allied health professional has been to work as part of the medical team providing treatment to patients to improve the physical and mental well being.

The problem, however, is that allied health professionals may not view this group of patients and the treatment of them to be a speciality or an area that deserves special training and expertise. In this regard, many allied health professionals who work with these types of patients do not have advanced knowledge or skills that make them truly effective. Those that do have advanced skills are few in number. Therefore, the quality of care from facility to facility may vary greatly.

Another aspect of the role of the allied health professional's input into the management of arthritic patients is that the other medical specialities and the public are not aware of the potential use that could be made of allied health professionals in treating these patients. Physicians, in some cases, do not know how to use other health personnel in helping them to carry out their treatment plan. The public generally is unaware that health professionals, other than physicians, may be able to effectively provide medical care at lower cost and just as effectively.

In view of the large numbers of arthritis patients and the large amounts of money spent both by the public and the government to make medical care available to these patients, there seems to be a need to educate both patients and health professionals, other than physicians, in the management of these patients.

Current Educational Status of a Specific Allied Health Professional--Physical Therapists

Physical therapists at the undergraduate level are given basic preparation and knowledge in the approach to arthritic patients. Their training consists of didactic as well as laboratory work in the therapeutic techniques applicable to arthritics. Also, during this time the students are taken to a local hospital (St. Margaret's) where a comprehensive view of treatment with patient demonstration is presented. Also during the student's clinical education, special projects are arranged for selected students to spend extra time studying the aspects of managing these patients. This clinical education experience is perhaps

the only time that actual emphasis or "specialty" training is given to students in this area. In essence, the students are provided a chance to gain a basic understanding of the problems and methods for treating arthritic patients. Little time is spent in going beyond this basic understanding and those that do are few in number.

#### Educational Needs of Allied Health Personnel and the Public

The team approach is obviously important in managing all of the medical aspects of arthritic patients. Some attempt should be made to educate medical personnel, not only physicians, in the medical management of these patients and how each would interact to provide the patient with the most realistic and effective treatment program.

The specific practitioners on the team, physical therapist, occupational therapist, social worker, psychologist, physician, nurse, should be provided with information as to their ideal role in this process and cooperative efforts of all of these people should provide maximum benefits to the patient. This would require advanced education of all of the team members in rheumatic diseases, their problems, management principles, prognosis, and follow-up studies as to the effectiveness of each person's intervention with the patient. Are we really doing the patient any good?

The public, just as the health practitioners, should be educated to the latest medical advances in management of rheumatic disease, the sources of care, and a system developed to make access to these services should be made obvious to the public. Quackery in this area of health is well documented. This aspect alone, if eliminated, would channel many dollars where it could do the most good.

It is suggested that advanced education be given to allied health personnel and the public. The need for increased education of physicians is important, but just that alone would solve only half of the problem. Allied health workers carry the burden of actual treatment. More and better trained people in this area, just as more and better trained physicians, will result in better care. The public needs to "know" about arthritis, all aspects of arthritis.

Submitted by: Jerome L. Martin, Associate Professor  
Department of Physical Therapy  
University of Pittsburgh  
School of Health Related Professions  
Pittsburgh, Pennsylvania

Robert W. Richardson  
Pittsburgh, Pennsylvania

#### APPENDIX IV

A self-instructional package, or module, is a self-contained, independent unit of a planned learning activity designed to help the learner accomplish certain objectives without reliance on others. There are several advantages to this form of instructional methodology.

- (1) It assists the learner to study and grow at his own rate (i.e., the learner determines the time, frequency and duration of his learning periods).
- (2) Self-instructional packages allow the learner to choose his own mode of learning (i.e., listening to audiotape, reading textbook and journal or watching audiovisual materials.)
- (3) Another advantage is the accessibility of this type of educational experience. Often many health professionals are not able to participate in continuing education programs due to time and distance factors. Self-instruction packages bring the educational experience to the learner and within his own time schedule.



TESTIMONY OF  
ROBERT W. RICHARDSON

RICHARDSON: Mr. Chairman and members of the Commission:

I appreciate the opportunity to share my views this morning. I am Robert W. Richardson. I represent the Western Pennsylvania Arthritis Project, St. Margaret Memorial Hospital, and the University of Pittsburgh School of Health-Related Professions. Appendix I, II, and III briefly describe their activities in arthritis care.

I believe our experiences have direct and important bearing on the future of arthritis care programs and services. My testimony is drawn from experiences made possible by these programs.

We have placed special emphasis on a system of diagnostic, therapeutic and rehabilitative services throughout western Pennsylvania, utilizing the existing personnel and resources. Services and programs are aimed at increasing the awareness of all who are affected by arthritis--the patients, doctors, allied health professionals, and the community in general.

The prime ingredient in the Regional Medical Program (RMP) Arthritis Project is our multidisciplinary approach which includes at least the following professionals: coordinator, orthopedic physician, medical physician, nurse, physical therapist, occupational therapist, social worker, and vocational counselor. We believe the diversity of disciplines ensures that the complexities of medical, psychosocial, and vocational problems which accompany arthritis are met as fully as possible.

To date, four regional arthritis facilities have been organized in communities outside Allegheny County, where none were previously built. Rapport was established with these Amish facilities by initial interviews conducted with the staff. These meetings discussed program objectives and determined gaps in their proposed care plan.

These gaps, being the goals, were subsequent orientation training courses for each facility's staff. The four deficiencies most commonly cited were:

- (1) Basic lack of knowledge of current practices in evaluating and treating the arthritis patient.
- (2) A multidisciplinary approach is generally not used.
- (3) Little communication exists among various health care disciplines.
- (4) Lack of awareness in the use of the available community resources.

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have been developed to train more practitioners with new skills in arthritis care.

Now we are working on self-instructional materials (Appendix IV) for professionals in the outreach facilities and under served areas. These materials incorporate such techniques as programmed texts and other self-instructional materials. This approach has wide application.

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In summary, then, the arthritis center consortia must be responsive to the arthritis patient's total needs, medical, emotional, social and vocational--channeling patients to the comprehensive care required.

The approach I've described means trained and fully utilized teams of professionals. I believe the most urgent requirement under the new Arthritis Act is for the support of educational activities:

- (1) Graduate Education--to train more professionals in the care of patients with arthritis, teachers, researchers and clinical specialists.
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The role of the allied health professional in the care of the arthritis patient must be more broadly and specifically defined. In most cases, they are not utilized to the extent possible. Their potential contribution to patient education, patient care, and community planning is enormous. Furthermore, funds must be appropriated to develop more and better model centers with the goal of truly meeting the needs of patients with arthritis by way of the best programming, clinical research, data collection and analysis.

Lastly, and I quote Mr. Martin's written testimony from the University of Pittsburgh, which is attached, "The public, just as health practitioners, should be educated to the latest medical advances,

resources, and care." The public needs to know about arthritis. Thank you.

ENGLEMAN: Thank you. Yes, Mr. Shields.

SHIELDS: Bob, you made the statement that the allied health people are not being utilized to their fullest extent. Would you care to comment as to, in your opinion, why they are not being utilized?

RICHARDSON: Well, I--in my opinion, I think that's a personal thing and just from our experience with our outreach activity, is probably twofold: Number one, they haven't been trained to be clinical specialists, and therefore they haven't been able to contribute the way we'd like to see them contribute; and probably, two, there's not enough physician awareness of their potential contributions. I think those two things coupled give the end result and my impression that they're not being utilized to the extent desirable.

ENGLEMAN: Thank you very much. We now proceed to hear from Dr. Ehrlich, George Ehrlich.

SUBMITTED STATEMENT OF  
GEORGE EHRLICH, M.D.  
PROFESSOR OF MEDICINE, TEMPLE UNIVERSITY  
DIRECTOR, ARTHRITIS CENTER AND DEPARTMENT OF RHEUMATOLOGY  
ALBERT EINSTEIN MEDICAL CENTER AND MOSS REHABILITATION HOSPITAL

The National Arthritis Act is supported on the three pillars of research, education, and patient care. There is no question that research into causes can ultimately be translated into development of better treatments, even cures. A definite shortage also exists in personnel capable of doing this research, and to remedy this shortage, reestablishment of training programs has been proposed. The third area, patient care, cannot wait until more personnel are trained or new important discoveries are made. The plight of the millions of arthritic sufferers requires that programs of patient care utilizing all that is known be instituted more widely.

Patient care encompasses the end product of research and training, and, if properly constituted, provides a setting for further research and training. Moreover, the type of educational training opportunities available at a properly constituted center prepares not just physicians to become specialists in rheumatology but rather also serves to train the many allied health professionals who will be responsible for bringing relief to arthritic sufferers.

A recent Canadian study suggested that up to 70 percent of arthritic sufferers treat themselves or, at most, consult their pharmacists. This number, however, includes many who have not been identified in vital statistics as being among the arthritic population. Therefore, it is likely that the number of arthritic sufferers is much larger than has previously been estimated. Moreover, although self-medication implies lesser severity of the disease, it does not follow that many of these



people would not have their lives eased if they had access to properly trained professionals. In this connection, training of pharmacists to help them refer people to more structured settings becomes one of the mandates of the program. Those arthritic sufferers who consult physicians because of their symptoms, thus becoming patients, are not always rewarded by optimal care, either. The reason appears to be the philosophy of crisis intervention which most medical schools and graduate training programs teach. Sufferers from chronic illnesses require more than crisis intervention: they require long-range plans based on an understanding of the natural history of their diseases and encompassing well-conceived efforts to alter that natural history favorably without introducing unacceptable risks. It is likely that no single physician can offer this kind of a program unaided by an interdisciplinary team. Even if only a minority of arthritic sufferers require such concerted efforts, it is a significant minority, numbering millions of Americans.

The concept of a team requires more than that representatives of the various components be available in a given community. A consultation type of relationship will not do the job. The team members must learn to work together, exchange appropriate information personally (and not only via written consultations), and maintain a relationship in which reports of progress or problems are noted by all. In other words, an arthritis center must be created, which represents a philosophic grouping, whenever possible, in a fixed geographic base.

The Arthritis Center of the Albert Einstein Medical Center and Moss Rehabilitation Hospital, developed in conjunction with Temple University School of Medicine, and participating under the Regional Medical Program in an Arthritis Control Project, serves as one such example. The details of structuring and philosophy are set forth in my book, Total Management of the Arthritis Patient (Philadelphia, J.B. Lippincott, 1973) in the Introduction and in Chapter 10, "Referral Resources." Other approaches to arthritis centers are also put forth in Chapter 10.

Basically, there are four different groupings within the team approach. These are medical, surgical, physical, and psychosocial. The medical team is represented by rheumatology, a recognized subspecialty of internal medicine. In our center, attending rheumatologists are augmented by clinical and research fellows, appropriate technicians and secretaries, an arthritis rehabilitation nurse specialist, and six consultants in radiology, ophthalmology dermatology, otolaryngology, gastroenterology, renology, and hematology. Fixed consultants mean that these particular persons have shown an interest in the diseases being treated and have voluntarily established a close relationship with the Arthritis Center program. As can be seen, this section of the program provides future clinical rheumatologists and research-oriented rheumatologists, the need for whom has already been demonstrated by other witnesses.

The surgical members of the team are orthopedic surgeons with special training in arthritis surgery. These men work within the team, not on a consultant basis but rather regularly. As the Arthritis Center has a 25-bed geographic unit within a rehabilitation hospital on the grounds of a large general hospital, fixed surgical rounds on a daily basis as well as combined rounds and conferences with the other members of the team are

possible. Also possible is the preparation of the patient for surgical procedures, his preoperative and postoperative care, adaptation of beds and rooms for special needs of operative patients, and training of all personnel in the preparatory and postoperative approaches to care. A consultant plastic surgeon is available for specialized hand reconstruction, although the arthritis surgeons are competent to deal with the majority of hand problems. Orthopedic and orthotic technicians are available. As a result, not only are all the newest procedures being performed, including total replacement surgery for all major joints (including ankles, shoulders, elbows, and wrists, in addition to knees and hips) but newer prostheses are designed and applied and orthotic devices are applied and designed to help surgical approaches become more successful. The role of the arthritis rehabilitation nurse specialist is particularly central to the surgical team's approach.

The physical aspects are supervised by a physiatrist, assisted by physical therapists and occupational therapists who specialize in arthritis care. This fixed team also provides the splinting needed for arthritic patients. Their participation in rounds and conferences is essential to the medical and surgical teams in helping assess day to day progress of the patient and in highlighting new problems as they arise. It is important to note that resident physicians in rehabilitation medicine and in orthopedic surgery are being trained at the Arthritis Center under the supervision of the appropriate seniors but as part of the team. Moreover, inservice training of physical therapists, occupational therapists, and nurses, both graduates and students, is carried out in this program.

The psychosocial area is covered by a psychiatrist, a clinical psychologist, and a social service worker. They participate on a full-time basis, and are augmented by vocational evaluation programs, vocational rehabilitation counselors, a program of transportation evaluation and transportation counseling and training and by audiology. Besides identifying barriers to rehabilitation, this team can help develop motivation and can serve to pinpoint problems in social, economic, and sexual spheres. They are able to maintain liaison with government agencies, such as the Bureau of Vocational Rehabilitation or the State Medical Assistance Programs, and with voluntary agencies, such as the Arthritis Foundation and other community agencies. In an imaginative development, the transportation counselor has obtained a bus for twice-weekly instruction of hospitalized and nonhospitalized patients in the use of public transportation and in the assessment of energy expenditure and architectural barriers as applied to public transportation. Complete driving instruction is available, and instruction for nondriving patients in transfer into and out of automobiles. A driving simulator has been set up. Of the other components, audiologic evaluation has proved fruitful in diagnosing unsuspected hearing deficits that have been barriers to patient education. Group psychotherapy sessions have been set up, as well as family teaching sessions, and verbal and practical intelligence evaluation and projective testing have identified organic brain syndromes, learning deficits and other barriers to reeducation that, when taken account of, have helped patients who might otherwise not have responded to orthodox approaches.



At the Arthritis Center patients who have major problems in multiple areas are discussed in lengthy team conferences with the full participation of all the identified team members, and the results of such deliberations are carefully discussed with the patients to enlist them as members of the treatment and rehabilitation team. Lesser problems are discussed by the whole team as well, especially for inpatients but for outpatients on appropriate occasions, in shorter conferences. Reevaluation of the program constantly goes on.

A strong and warm relationship with the patients is established through this program. The integrated approach of multiple medical, surgical, and allied health professionals is important to bring the optimal care to the more severely involved patients, but, modified, is still necessary even for those only minimally afflicted or at the early stages of their diseases. One of the complaints about modern medicine (that it is impersonal and that the old doctor-patient relationship has been sacrificed in the interest of greater scientific medicine even if the results of treatment are more successful) is thus blunted.

The success of the program in our Arthritis Center has prompted others to emulate our approach. Several centers throughout the country, either now developed or in the process of developing, have sent personnel to observe our program and have asked personnel from our center to advise them in the development of their programs. Variations are inevitable, as the needs in some rural areas may be different from those in some urban areas. Nevertheless, the general concept of bringing interested personnel from a number of areas within medicine and the allied health professions together to work as teams can best provide proper patient care today and a training program for improvements in care, discovery of causes, and better research for tomorrow.

Please note that the personnel of our Arthritis Center are currently engaged under the Regional Medical Program Arthritis Control Project for Greater Delaware Valley in the training of allied health professionals. For the purposes of this program, we have identified allied health professionals who deal with arthritic patients and often may be the first to see them as: physical therapists, occupational therapists, nurses, social service workers, podiatrists, optometrists and pharmacists. The last three categories are being included in such a program for the first time. Our increased realization that the various eye diseases are commonly seen as part of rheumatic diseases and that some of our medications may have consequences to the eye has led to the inclusion of optometrists whom many people consult for such problems. The pharmacists have been included as has already been mentioned, because their advice is often sought by potential patients in lieu of medical consultation. Finally, podiatrists see many problems involving the feet that reflect arthritis, and their participation in treatment programs at arthritis centers is also essential. Thus, we are still developing interdigitating relationships with numerous professions. At no time have we lost sight of the fact that the patient spends the majority of his time with his family and other nonmedical people, including friends, employers, and fellow workers. Thus, the community has been drawn into the program, and we have developed programs that permit increased awareness of arthritis problems



in the community, beginning with the family and extending to those more remote as well.

Rehabilitation is not merely a set of procedures applied to someone who has already lost the ability to care for himself. Rather, rehabilitation is a set of attitudes applied to all patients, no matter how minimally involved: to prevent arthritis from interfering with independence; to teach society at large the needs of those afflicted with the arthritic disorders; to prevent the setting up of architectural and other barriers which limit life space for the arthritic patient; to keep the arthritic sufferer a productive member of society (able to pay taxes rather than being on the receiving end only); and to develop justifiable optimism in those treating and those treated alike. We hope attention will be paid to the importance of rehabilitation when the aims of the Arthritis Act are finally discussed and appropriations are being considered.

TESTIMONY OF  
GEORGE EHRLICH, M.D.

EHRLICH: Thank you, Dr. Engleman. Ladies and gentlemen of the Commission:

I am George Ehrlich, a professor of medicine at Temple University, and Director of the Arthritis Center and Department of Rheumatology at Albert Einstein Medical Center and Moss Rehabilitation Hospital in Philadelphia.

I believe I was asked to come here before the Commission because the arthritis center that we have developed during the last 11 years, and in part initially through funding from the Commonwealth of Pennsylvania several years ago, embodies in principle and in practice many of the concepts that Dr. Decker has just left with us.

In addition, because of our orientation, and especially because of our recognition that the need for a team approach means not just physicians but the professionals in the health sciences and the patients themselves, we have been involved in the Regional Medical Program of the Greater Delaware Valley, which Dr. Tourtellotte and Mr. Salmon addressed themselves to previously, in the development of an educational program for allied health professionals.

I'd like to speak, however, as an individual. I have left with you a presentation which details our arthritis center functions, and how we believe arthritis centers might best be constituted under the double concept of total care. I personally feel that the moon-shot approach is valid for some scientific discoveries, but not valid in dealing with chronic diseases. In other words, I'm not quite certain that a moon-shot approach is going to yield the answers to arthritis. I think that it is more likely that answers will come if we have various centers throughout the country. And, in answer to Dr. Sharp, I would say more centers rather than less centers.

Now, these centers should look into the future. These centers are regional centers; they draw from an area. Obviously, there's not going to be a rheumatologist on every corner. However, a triage sort of system can be developed which will lead patients to the proper places for them. And I say to the proper places for them because a recent Canadian study has demonstrated that, there, at least, 70 percent of the people who have arthritis do not ever consult a physician for this arthritis, but, rather, treat themselves or consult their pharmacists. That means that only 30 percent of the people consult their physicians. And, if the referral patterns are true, only 10 percent reach the rheumatologist.

We rheumatologists, therefore, have a rather preselected view of what the arthritic disorders are. And we're probably missing many of the disorders of the field that we cover that are not particularly serious and that can, perhaps, be managed as implied in this statistic.

I think that the lessons of the Viet Nam War, the evacuation, the type of system that the Army set up with an ever-increasing sophistication towards the center is going to work in medicine in the future, and it is something we must plan for.

But, just as chronic diseases are not acute diseases, chronic diseases require a different approach. There must be two things borne in mind: One is long-range planning in terms of the natural history; and the second is crisis intervention, the crisis intervention that requires that we do something about what the patient complains of.

For the body politic, especially that segment dealing with health care, that means that the long-range planning is research and training, but the crisis intervention is a coordination of existing facilities, not necessarily even training or new facilities.

Under the philosophy of rehabilitation, which perhaps (inaudible) the doctor-patient relationship that we have heard is so lacking, only not in a single individual, but in a group of people, we must emphasize the humanity of our patients, by recognizing that "patient" is a role played by a person when he comes in contact with the health establishment. This same person in other roles is father or mother, sister or brother, employee or employer. And, finally, we must recognize the place of this person who has arthritis in his community and in his family, and the interactions that take place in both directions.

Now the teams constituted to deal with this require a quarterback. But the quarterback can't do it alone. He needs 10 offensive linemen, offensive players and he needs 11 defensive players, or else there is no team.

By the same token, the team here will have rheumatologists and orthopedists interested in arthritis. But it requires nurses trained in rehabilitation; it requires physical and occupational therapists and social service; it requires podiatry, because, often, the podiatrist is the first to see the patient and perhaps he is not able to recognize arthritis and get the patient to the proper channels.

It should involve pharmacy because, as I've already stated, the pharmacist is often the first one the patient asks what to do about his symptoms. It should involve optometry because of the many problems involving the eye, and the fact that most people consult an optometrist and not the physio-ophthalmologist for these.

Vocational counseling must be involved, transportation counseling, psychology, psychiatry, and the many related medical and surgical specialties, although some of these might be on an ad hoc patient basis.

And, finally, we must not forget that the team involves the patient and those people who interrelate with the patient. Under those circumstances, however, we must reach out. And I think the arthritis center's important function is to deal with the minority of patients who need arthritis care, but those who need arthritis care of the most intensive nature, with the cooperation of all these personnel.

And the arthritis center must serve as an educational base from which to reach other people whose influences upon the arthritic is at least as great as the influence of the disease or the influence of the treatment programs. These people are architects who put revolving doors in buildings and put in ceremonial staircases which effectively prevent patients from using what the community has to offer. We must reach industrial designers who make lower toilets, and lower cars which constantly make it difficult for the patients to get around and restrict the life space.

We must reach employers and unions to point out the valuable role that the arthritic patient may still play. As the gentleman who testified previously--who obviously has ankylosing spondylitis which is not incompatible with continued activity--as he mentioned, such a person can fulfill a job. Sometimes only some small variations like being able to park closer to the building in an assigned spot--all this might make it possible for such a person to contribute to society by paying taxes and working rather than taking tax monies.

We must talk with the insurance industry, and we must enlist the aid of government. If all these things are done, then the work of the Arthritis Commission in recommending arthritis centers, whether these in some places be based in universities and be highly specialized, or whether they are for the state as a whole or for a region as a whole, the work of the Commission will be successful because within the environment thus created questions will be asked and answers will be forthcoming. Thank you.

ENGLEMAN: Thank you, Dr. Ehrlich. Yes.

MELICH: I'd like to ask you how you feel a patient can be involved in the arthritis team, in the actual arthritis team approach?

EHRlich: I can only illustrate it by showing what we do. We have these clinical conferences, that Dr. Decker referred to. And at these clinical conferences the patients are not present. We hear about the patient's social contacts as well as his medical, surgical, and physical



appraisal. Decisions are made, recommendations are made. These are brought to the patient.

Then the patient is involved in the decision-making process. He is told alternatives. And, although it is true that an unprepared mind given alternatives will not know how to choose among them, we attempt to prepare through group teaching, group psychotherapy, through family conferences, and through a number of other constellations in which the patient is maximally involved so that he begins to understand the problem, and he can make an appropriate decision. We do this for outpatients as well as for inpatients.

Obviously, however, having inpatients in a geographic center permits this kind of interpatient communication which teaches the patient not only to make decisions with us, but also what some of the results are likely to be. We don't have to say that if you have a total elbow replacement or a total knee replacement, such and such a thing will happen. The patient sees people who have had such things. But, of course, we're talking about those patients who are most severely involved.

As I said before, for many arthritic patients the relatively more minor approach that apocryphally was attributed to (inaudible): "When the arthritic patient comes in the front door, I go out the back door."

ENGLEMAN: Yes, Dr. Whedon.

WHEDON: I think we're very interested in possible prototypes for centers that have been in existence already. You've been directing a center for 11 years. Could you briefly tell us a little bit about it in terms of its organization, how many doctors, how many allied health personnel, and whether there are regular meetings? How do you do it?

EHRlich: I believe you've known me long enough to know that that's one thing that's rather difficult for me to do--to be brief, but I'll try. Actually, I have mentioned some of this in my written presentation to you and elaborated on it in a recent book that we did based on the center concept, called The Total Management of the Arthritic Patient, published in 1973, and further details will be apparent in that. So most specialties within the center have a single individual who works closely within it to provide a face-to-face contact that is so important rather than the written contact.

Obviously, in the medical area we have rheumatologists. We have 2 full-time rheumatologists, and we have 6 rheumatologists who provide at least 50 percent time to the center--most, in fact, on a voluntary basis because they derive so much from it.

We have one orthopedic surgeon who is trained in arthritis surgery. We have one physiatrist. We have two physical therapists. We have two occupational therapists, one social worker, one psychiatrist, one clinical psychologist and one rehabilitation nurse specialist who supervises four registered nurses. We have a transportation counselor who is an occupational therapist trained in the means of transportation, both public and private, and driver training, and we have a simulator for this.

Now helping all these people, of course, we have a vast number of people. We have a biomechanics laboratory. We have, on the floor where the patients are housed, an ophthalmology examination and treatment room. We have a rheumatologic laboratory. We have an immunology laboratory that works closely with the Department of Nuclear Medicine for the application of some of the newest approaches to immunologic research, so that there is a research background for this. But, basically, the center is comprised of 25 beds in a geographic unit and augmented by an outpatient area that is in daily operation.

Now, in addition to the people I've mentioned, there obviously are fellows in rheumatology. We currently maintain four, not one under the training grant. Unfortunately, we started too late to put in for one of the NIH grants, and this never came under the training grant. But we have managed, so far successfully, to find support for four fellows.

We also train residents in orthopedics, medicine and physical medicine and rehabilitation, not only from Albert Einstein but also from Temple University. We have an orthopedic resident from Vanderbilt University for a year. We have residents from the United States Naval Regional Medical Center in Philadelphia, formerly the Naval Hospital, and we have students from Temple University and our electives from other universities, including Dr. Sharp's university, the University of Missouri, who have come for elective periods within the center, so that the staff has obviously swelled.

In terms of allied health professions we provide in-service training for students in the schools of allied health professions at Temple University and at the University of Pennsylvania. And we have provided a facility where other professionals throughout the states--nurses, physical therapists, occupational therapists, vocational rehabilitation counselors under the state, and others--come to the facility to participate in conferences, to see what we do, to get private, personalized inservice training for various periods of time by mutual arrangement.

ENGLEMAN: Did that answer your question, Dr. Whedon?

WHEDON: Thoroughly.

SHARP: Just a brief, ancillary question: The four rheumatology fellows you're training, is this for a 2-year or a 1-year period? And, can you just tell us what their program consists of?

EHRLICH: Very briefly, there are 2 per year for a 2-year period, so that makes 4 at the present time--2 second-year, 2 first-year men. Their programs begin by going to the rheumatology inservice floor where they take care of patients, admit patients, and supervise patient care and are able to be trained in some of the more severe problems.

They are then taken to the outpatient clinic, subsequently, in rotation, where they work with outpatients. They are sent on consultations throughout the hospital. They participate in the arthritis clinic at the U.S. Naval Hospital, and they participate in some of the many academic educational conferences throughout the Philadelphia area.



They also, then, go into the laboratory of their choosing. I believe that they should have about a year under their belts before they go into the laboratory so that they identify areas where they want to know more, rather than my assigning them a specific program, and then they have the options of working in biophysics and biokinetics, in immunology with the Department of Nuclear Medicine--that is, the Laboratory of Nuclear Medicine, or research work in our own laboratory.

So that follows throughout the second year. But while they are in the laboratories doing this work, they do not lose the patient contact because they continue at that point to see outpatients on a more limited basis, participate in clinic programs, and particularly, participate in the many seminars and programs.

One thing they always sit in on throughout their whole 2 years is these clinical conferences that Dr. Decker referred to, which we have in depth or at length for a patient who presents a particular problem, where an hour or more may be spent detailing the future, and the mini-conferences that are held for every patient, hospitalized, on a weekly basis, and also the clinic conferences that are held in clinic for outpatients.

ENGLEMAN: Thank you, Dr. Ehrlich. We must go on now. Dr. Eisenbeis.

SUBMITTED STATEMENT OF  
CARL EISENBEIS, M.D.  
MEDICAL DIRECTOR  
COMPREHENSIVE CARE AND REHABILITATION PROGRAM  
UNIVERSITY OF PITTSBURGH-St. MARGARET MEMORIAL HOSPITAL

I am here as the Medical Director of the Comprehensive Care and Rehabilitation program, Arthritis Division, of St. Margaret Memorial Hospital of Pittsburgh; as the Medical Director of the Western Pennsylvania Arthritis Project of St. Margaret Memorial Hospital and the University of Pittsburgh's School of Health Professions; and representing the Western Pennsylvania Chapter of the Arthritis Foundation.

Optimal care for the patient with rheumatic disease can be delivered by health professionals working as part of an integrated team. Nurses, physical therapists, social workers, occupational therapists, clinical psychologists, orthopedic physicians, rheumatologists, physicians who deliver primary care and patients with arthritis must function as an interrelating, multidiscipline, well organized structure if the patient member of the team is to reach his potential for maintaining physical, social and psychological maximums in the face of what is often relentless, progressive diseases.

The only component of the team I have just described that is not in short supply is the patient with arthritis; and opportunity for this component of the team to become knowledgeable about his disease, in spite of the effective but necessarily limited activity carried out by the chapters of the Arthritis Foundation in Pennsylvania, is only minimal. That minimal is still greater than the opportunity presented to most health



professionals interested in improving their knowledge of the disease. I submit for your reference the report of the survey of the Arthritis Foundation's Professional Education Committee of June 3, 1975, which I am sure you have had an opportunity to review.

A portion of that survey report which I believe needs emphasis demonstrates what must be considered minimal participation by medical students and house staff in educational programs related to rheumatic diseases; this lack of opportunity is less striking at the University affiliated than at the non-University affiliated centers, but striking and astounding nonetheless.

These facts must at least suggest, and my experience with our St. Margarat Memorial Hospital-University of Pittsburgh Arthritis Project, and experiences gained in the training of residents coming to our institution from 'round the country for training in the newly developed field of Family Practice, and my learning opportunity with the Western Pennsylvania Comprehensive Health Planning Association, confirm that there is a very large reservoir of willing and eager to learn practicing and about-to-practice primary care physicians and allied health professionals who are woefully lacking in basic knowledge regarding the care of the patient with rheumatic disease.

I, therefore, recommend that the National Arthritis Commission give strong consideration to the development and enlargement of programs for the education and training in rheumatic disease of both patients afflicted and the presently-practicing or about-to-practice vast professional manpower resource which I have just described; the Commission must, of course, consider as well the more obvious need to train medical students and post-graduate specialists in the field of rheumatic disease.

My experience with the Comprehensive Health Planning Association of Western Pennsylvania as an advisory planner for the delivery of health care necessitates that I emphasize one other point. That Western Pennsylvania and, indeed, the entire nation is in need of the development of facilities alerted to the total spectrum of rheumatic disease from research to education to delivery of care, is unequivocal. However, some functioning facilities do exist, both university affiliated and "free-standing"; it would be abhorrently wrong for these facilities to be duplicated by programs sponsored under the Arthritis Act in the sincere but, perhaps, misguided rush to get the job done.

I recommend, therefore, that consortia be not advised but in many areas mandated as necessary to avoid the unfortunate pitfall that so frequently faced health planners in the past--the duplication of facilities at the enormous expense of the taxed and the ill.

## REPORT TO THE MEDICAL ADMINISTRATIVE COMMITTEE

JUNE 3, 1975

## ARTHRITIS FOUNDATION

## PROFESSIONAL EDUCATION

## COMMITTEE SURVEY

This survey was conducted in behalf of the Professional Education Committee of the Arthritis Foundation. Its purpose, in broad terms, was to gain some perspectives of the staffing, training, educational activities, program commitments, program expenditures, and perceived needs of the arthritis programs throughout the United States.

Questionnaires were sent to all 114 medical schools listed in the AAMC Directory - 1974; to all institutions listing medical residency programs in the Directory of Approved Internships and Residencies 1973-74, and to a diverse group not listed in either of the above but known by the Arthritis Foundation to have rheumatologists involved in patient care, and/or research in arthritis. Where known, the questionnaires were sent to the arthritis program directors, and where unknown, to the chairmen of the departments of medicine in the institutions. Altogether 132 questionnaires were mailed and 131 responses are included in this report. This includes 41 of 42 institutions designated as Arthritis Clinical Research Centers (recipients of Arthritis Foundation center grants), 51 medical schools not designated as arthritis centers and 39 others belonging to neither of these categories.

Of the 114 medical schools, 94 submitted completed questionnaires. Of the latter, only one has a full-time or part-time staff rheumatologist and the remaining 7 have no staff rheumatologist, or any activities either in research or education specifically devoted to arthritis. A total of 15 medical schools have no arthritis program.

Difficulties in the definition of terms and in obtaining the fiscal information precluded the use of any questions related to program budgeting and expenditures.

Staffing of arthritis programs was usually small, 16 institutions having no full-time M.D.'s, 25 institutions having only one full-time M.D., and 26 institutions having only 2 full-time M.D.'s. Ninety institutions had no full-time Ph.D's. Thirty-four institutions had no part-time M.D.'s and 25 institutions had only one part-time M.D. Total staffing in all programs included: full-time M.D.'s 415, full-time Ph.D's 70, part-time M.D.'s 327, and part-time Ph.D's 28.

Many programs had no postdoctoral fellows and other programs had very few such trainees. Specifically, 77 programs had no M.D.'s on clinical fellowships, 110 programs had no M.D.'s on research fellowships, 114 programs had no Ph.D's on research fellowships, and 78 programs had no M.D.'s on mixed clinical and research fellowships. Total postdoctoral trainees included: clinical 115, research M.D.'s 53, research Ph.D's 30

and mixed clinical-research M.D.'s 130. A total of 52 institutions had no fellowship positions available in 1973-74. Only 229 new fellowship positions were available that year.

There were relatively small numbers of house staff and medical students participating in these arthritis programs: Over half of the institutions had only 0-15 house staff participating in their program during the year and only very rarely were house staff from non-university-affiliated hospitals involved in these arthritis programs. About two-thirds of the institutions had a total of only 0-15 medical students participating in the arthritis program during a year.

Many programs had little or no allied health professional participation. There were no physical therapists participating in 35 programs, no occupational therapists in 52, no social workers in 47, no nurses in 42, no psychologists in 100, no vocational rehabilitation specialists in 98 programs. Eighty-one programs had no allied health professional students.

The highest educational priorities of most arthritis programs were for house staff, rheumatology fellows, and medical students. Continuing education for nonspecialist and specialist physicians was usually a lower priority of these arthritis programs. Training of allied health professionals and postdoctoral training in orthopedic surgery and physical medicine and rehabilitation were usually of a very low priority or not even included in the program.

Ninety-five of the responding institutions conducted arthritis professional education programs in other institutions during 1973-74. Local Arthritis Foundation chapters frequently did not support the institution's professional education programs.

Over two-thirds of the institutions believe that there were inadequate numbers of rheumatologists in their medical community and within their institutions to carry on their present professional education programs. Physiatrists, orthopedic surgeons, allied health professionals, and family physicians were cited somewhat less frequently as being inadequate for their present arthritis educational programs. Most institutions felt that an increase of one or two professional staff M.D.'s and rheumatology fellows would be necessary to establish an optimal educational program. Almost two-thirds of the institutions would require additional allied health professionals and basic scientists for an optimal educational program. Most programs felt that they could not increase their professional educational activities inside or outside their institution without increased funds being available.



TESTIMONY OF  
CARL EISENBEIS, M.D.

EISENBEIS: Thank you, Dr. Engleman. I am Dr. Carl Eisenbeis. I, too, appreciate very much the opportunity to testify here this morning.

I am here as the Medical Director of the Comprehensive Care and Rehabilitation Program, a major clinical section of the University of Pittsburgh's rheumatology program at St. Margaret Memorial Hospital in Pittsburgh; as the Medical Director of the Western Pennsylvania Arthritis Project at St. Margaret Memorial Hospital and the University of Pittsburgh School of Health Professions; and representing the Western Pennsylvania Chapter of the Arthritis Foundation.

Optimal care for the patient with rheumatic disease can best be delivered, as has been indicated on at least two other occasions this morning, by health professionals working as part of an integrated team. Nurses, physical therapists, social workers, occupational therapists, clinical psychologists, orthopedic physicians, rheumatologists, physicians who deliver primary care, a variety of other medical specialists, and, most important of all, patients with arthritis, must function as an interrelating, well organized structure if the patient member of the team is to reach his potential for maintaining social and psychological maximums in the face of what is often a relentless and progressive disease. I agree with both Dr. Decker and Dr. Ehrlich that comprehension of an existing program, a structured program for the arthritic without a multidisciplinary approach is beyond me.

The only component of the team I have just described that is not in short supply is the patient with arthritis. And the opportunities for this patient component of the team to become knowledgeable about his disease, in spite of the effective but necessarily limited activity carried out by the chapters of the Arthritis Foundation in Pennsylvania, is only minimal. That minimal participation is still greater than the opportunities presented to most health professionals interested in improving their knowledge of the disease. I submit, again, for your reference the report of the survey of the Arthritis Foundation's Professional Education Committee of June 3, 1975, which I am sure you've had an opportunity to review, and which I have appended to my testimony.

A portion of that survey report, which I believe needs emphasis, demonstrates what must be considered minimal participation by medical students and house staff and allied health professionals in educational programs related to rheumatic disease. This lack of opportunity is less striking at the university affiliated than at the nonuniversity affiliated centers, but striking and astounding to me, at least, nonetheless.

These facts must at least suggest, and my experience with our St. Margaret Memorial Hospital-University of Pittsburgh Arthritis Project, and experiences gained in the training of residents coming to our institution from around the country for training in the newly developed field of family practice, and my learning opportunity with the Western Pennsylvania Comprehensive Health Planning Association confirm, that there is a very

large reservoir of willing and eager-to-learn practicing and about-to-practice primary care physicians and allied health professionals who are woefully lacking in basic knowledge regarding the care of the patient with rheumatic disease.

I therefore recommend that the National Arthritis Commission give strong consideration to the development and enlarging of programs for the education and training in rheumatic disease of both patients afflicted and the presently practicing or about-to-practice vast professional manpower resource which I have just described. The Commission will, of course, consider as well the more obvious need to train medical students and postgraduate specialists in this field.

My experience with the Comprehensive Health Planning Association of Western Pennsylvania as an advisory planner for the delivery of health care necessitates that I emphasize one other point: that western Pennsylvania--and, indeed, the entire nation--is in need of the development of facilities alerted to the total spectrum of rheumatic disease from research to education to delivery of care is unequivocal.

However, some functioning facilities do exist, both university affiliated and free standing. It would be abhorrently wrong for these facilities to be duplicated by programs sponsored under the Arthritis Act in a sincere rush to get the job done. I recommend, therefore, that consortia be not advised, but in many areas mandated, as necessary, to avoid the unfortunate pitfall that so frequently faced health planners in the past: the duplication of facilities at the enormous expense of the taxed and the ill. Thank you very much.

ENGLEMAN: Thank you very much, Dr. Eisenbeis. Any comment or questions?

(No response.)

ENGLEMAN: Time is running short. We have a deadline to meet at 2 o'clock, so I hope that those who will present testimony will keep this in mind. Jo Anne White.

SUBMITTED STATEMENT OF  
JOANNE WHITE, R.N.  
REHABILITATION COORDINATOR  
ST. MARGARET MEMORIAL HOSPITAL

I would like to address the following remarks to the Arthritis Commission:

I am a registered professional nurse currently working in the field of arthritis in the western Pennsylvania area. Being aware of the Commission's public hearing, I composed a 15 item questionnaire which I asked 50 patients to complete, asking them how they, personally, felt their needs as arthritis sufferers could best be met. All of the patients are presently under the care of an arthritis specialist and all have been diagnosed with arthritis of some type. The questionnaire was distributed

in the waiting rooms of six area rheumatologists and in St. Margaret Memorial Hospital, Pittsburgh, to inpatients. All were adults of random ages and sex, coming from a wide geographic area encompassing most of western Pennsylvania. Patient names were not asked and a brief statement in writing accompanied each questionnaire explaining the purpose of the study. The explanation read as follows:

"To our patients:

"The recent passage of the Arthritis Act has brought increased attention to the nation's number one crippling disease. Since over 20 million Americans, one 10th of our population, are afflicted by arthritis, we as health professionals, are committed to helping secure the attention and national support this health problem deserves.

"As one way of calling attention to the needs of persons afflicted with arthritis, we are asking you to fill out the following questionnaire so we can identify what type of education, help and care you feel you need and deserve as patients, citizens, and consumers. We will then take the results and your recommendations to a public meeting held in Harrisburg on October 14, and share the results and your feelings with the Arthritis Commission.

"Hopefully, by calling attention to this critical problem in this way, we can better meet the needs of people afflicted with arthritis and provide better quality care in the future."

I would like next to submit the results of this questionnaire to this commission. They are as follows:

Question 1 confirmed that all patients had some form of arthritis.

Question 2 asked for the length of time the patient has had arthritis. The time ranged from 5 months to 40 years.

Question 3 asked: How did you first decide you had arthritis?

82%--doctor told me I had it

16%--figured it out myself or talked with friend

2%--another medical person told me

Question 4 asked the following: If you learned you had arthritis from a doctor, was this person a general practitioner, a specialist in arthritis, or another kind of doctor?

54%--general practitioner

36%--specialist in arthritis

10%--other



Question 5 asked: Did you receive any treatment of any kind for your arthritis before you came here?

74% responded YES

26% responded NO

Question 6 asked: "If you received any treatment for your arthritis before coming here, what was it?" Most answers centered on prescribed medication. Very little therapy was mentioned. One person stated X-rays were prescribed, and another said his doctor told him his case was hopeless. One man who gave his name stated, "You name it, I tried it, from gold shots to seawater, to copper bracelets to acupuncture."

Question 7 asked, "Was the prior treatment helpful?"

26% responded YES

48% responded NO

26% chose not to answer the question

Some said they got worse and some said their doctors told them they needed special care. One said--and I quote, "The doctor at the clinic said help for the swelling wasn't available. I could hardly walk because of swollen ankles, so I went elsewhere."

Another stated, "No regular program or schedule was worked out for me; no guideline given me."

Question 8 asked if they felt people with arthritis needed special care due to the nature of the disease.

100% responded YES

Question 9 inquired if they personally felt they required special care to manage their arthritis.

96% responded YES

4% stated NO

This is not surprising considering the high percentage of people dissatisfied with treatment prior to coming to an arthritis center or a rheumatologist.

Question 10 asked the following: "If you feel you need special care, how important do you feel each of these are:"

special hospital or treatment center

specially trained doctors

specially trained medical people other than doctors

home services

special screening clinics

instructional information to read and learn yourself

educational programs taught by specially trained people

messages and programs over the media

Patients were asked to rank them as very important, important, or not important. All items were considered important or very important by over 90% of the respondents. In order of importance they ranked the items as follows, from most important to least important:

- (1) specially trained doctors
- (2) specially trained medical people
- (3) special hospitals and treatment centers
- (4) educational programs taught by specially trained medical people
- (5) self-instructional material
- (6) special screening clinics
- (7) messages or programs over the media
- (8) home services

Question 11 asked if anything more than that mentioned above could help, what would it be. All respondents left this blank.

Question 12 stated: "Putting together all the things you know about arthritis, where would you say you have gotten your information about your disease and treatment?"

Options were doctor, nurse, physical therapist, occupational therapist, social worker, word of mouth, reading, personal experience, others with arthritis, don't know, or other. Answers were fairly evenly distributed and most people indicated they got their information from more than one source, often more than two or three.

Question 13 asked: What do you regard as the most useful source of information? Options given were the same as those in No. 12. Again, a variety of sources were felt to be the most useful source. Over 56% gave more than one source as useful. One person said, "Don't regard one source as important, all are necessary." Another commented, "Any source--I still don't know too much about it." This person, incidentally, gave a history of having arthritis for six years.

Question 14 asked how the person heard about their present doctor:

26%--referred by friend

14%--family member

18%--another arthritis sufferer

42%--family doctor

Indicating a variety of referral sources.

Question 15 asked if it was difficult to locate a specialist or treatment center. Some 32% said yes while 68% said no, due to many referrals by the family physician. Of those who said it was difficult, some said specially trained people were not easily available where they lived and others said they just were not aware specially trained people existed.

The last statement of the questionnaire asked for comments of any kind that the person wished to make. Three of the people took time to comment, which I feel is significant after filling out a lengthy questionnaire.

Most of these comments asked for more programs for people with arthritis and the need for specially trained people to give good care and to understand the needs of people with arthritis.

I have selected three comments to quote:

- (1) "Instructional classes held while in the hospital were most beneficial to me. Proper care of inflamed joints by doing tasks properly were most helpful. Also learning the names of medications one should and should not take."
- (2) "The people need a better education about the disease and not treat it lightly."
- (3) "I feel an educational program would be very beneficial to arthritis because it seems to me most people just take a pain killer. Also, since many people suffer agony continually, it would be very beneficial to have more personnel trained to treat arthritic people."

My conclusions are as follows:

- (1) Patients surveyed in the western Pennsylvania area felt care prior to coming to a rheumatologist or special treatment center was not adequate.
- (2) Patients surveyed in the western Pennsylvania area felt an overwhelming need for specially trained teams of not only physicians but nurses and other allied health professionals to work together to not only give quality care and help patients manage their disease, but to help educate them through planned programs.



- (3) Educational preparations at all levels for nurses and other allied health professionals in the western Pennsylvania area to provide specialty care for the needs of the patient with arthritis are virtually non-existent, other than the Western Pennsylvania Arthritis Project. The funding for this project ends June 31, 1976.

My recommendations are brief:

- (1) Adequate funding is necessary in the western Pennsylvania area to provide a variety of needed programs to adequately care for the patient with arthritis and to help educate him so he can better manage and understand his disease.
- (2) That the Arthritis Commission consider the data presented as valid evidence of a demonstrated need for programs essential and critical to the basic care of those afflicted with arthritis.
- (3) Since educational programs for preparing nurses and other allied health professionals for coping with the arthritis patient are grossly inadequate in the western Pennsylvania area, an organized effort to close this gap is recommended through a variety of programs, particularly continuing educational programs designated for those presently caring for the patient with arthritis.

TESTIMONY OF  
JOANNE WHITE, R.N.

WHITE: Mr. Chairman, and members of the Commission: I'd like to address to you the following remarks, and I'll skip over a few things because I know time is of the essence.

My name is Joanne White. I am a registered professional nurse, and I take care of patients with arthritis. Being aware of this public hearing I wanted to gather up all my patients and bring them with me, but since finances could not afford that, I asked them to fill out a questionnaire. Instead of telling you what I think, I'd like to tell you what my patients think. I gave them 15 questions to answer in the waiting room of six area rheumatologists, and in the inpatient setting at St. Margaret Memorial Hospital in Pittsburgh, and I'd like to share just a few of those figures with you today.

The first questions just confirmed that these patients did have arthritis, and the time range that they had had arthritis--from 5 months to 40 years--so I think the range is certainly sufficient to indicate that the patients are experienced with arthritis.

As far as identifying how they determined they had arthritis, many of them stated that a general practitioner first identified it and others said they had figured it out for themselves.

As far as treatment before coming to a rheumatologist, many of them stated the treatment was inadequate, and I'd like to throw out to you the figure of 74 percent, which I think is a significant figure.

Some said they got worse, some said their doctors told them they needed special care, and one I'd like to quote said, "The doctor at the clinic said help for the swelling was not available. I was a hopeless case. I could hardly walk because of swollen ankles. So I went somewhere else."

I asked them in the questionnaire if they thought people with arthritis needed special care due to the nature of their disease. An overwhelming 100 percent responded, "Yes". I also asked them if they personally felt they needed special care to manage their arthritis, and 96 percent said, "Yes". I don't think this is surprising considering the high percentage of people that I found terribly dissatisfied with care out in the country and out in the community.

Question 10 asked, "If you feel you needed special care, what kind of special care do you want us to give you?" And I asked them in a rank order as "Most Important," "Very Important," or "Not important at all" eight items. Over 90 percent of the respondents felt that these eight items were most important: specially trained doctors, specially trained medical people other than doctors, special hospitals and treatment centers, educational programs taught by specially trained people, self-instructional material, special screening clinic, messages over the media and home services.

Questions 12 and 13 indicated that a variety of sources of information were utilized by patients either to find out information or that they identified would be helpful ranging anywhere from allied health professionals, along with physician teams, down to self-education. They felt that no one modality was important but a combination of many.

Question 15 identified that it was difficult for 36 percent of our patients to find treatment centers, and many said they didn't even know special people existed.

The last segment of the questionnaire asked for comments, and I left 8 blank spaces or 10, or whatever, and asked them to just let us know if there was anything else they wanted us to bring to the Commission hearing. Most of these comments asked for more educational programming for patients with arthritis and they stressed the need for specially-trained people who are presently caring for people in inpatient settings and clinics and treatment centers.

I collected three brief comments I'd just like to share with you. One person said, "Special classes while held in the hospital were most helpful. Proper care of inflamed joints by doing tests properly were most helpful, and learning the nature of the medications I should take and what I shouldn't take." The second person said, "People need a better education about the disease in general, and not to treat it lightly." And the third person I've chosen to quote said, "I feel an educational program would be very beneficial because it seems to me most people just take a pain

killer." Incidentally, this person felt an overwhelming need not only for specialized care but for educational programs.

And third, from my own personal investigation, I'd like to say that educational programs at all levels for nurses and other allied health professionals is nonexistent in the Pittsburgh and western Pennsylvania area, other than in the Western Pennsylvania Arthritis Project, which is the only one I'm aware of.

My recommendations are brief: One, that adequate funding be appropriated to the western Pennsylvania area for a variety of programs to adequately care for those patients who have arthritis; second, that this Commission consider the data that I have presented both in verbal testimony and in written form be considered as valid data to demonstrate the needs for these programs in our area; and, third, since programs for preparing nurses and other allied health professionals is so totally nonexistent and lacking in our area, that an organized effort be made to close this gap is recommended through a variety of programs, particularly continuing educational programs for those presently caring for the patient with arthritis. Thank you.

ENGLEMAN: Thank you for a most unique presentation--very concise. Any comments or questions from members of the Commission?

(No response.)

ENGLEMAN: If not, we will proceed then, to Barbara Winger.

TESTIMONY OF  
BARBARA WINGER  
STAFF OCCUPATIONAL THERAPIST  
ST. MARGARET MEMORIAL HOSPITAL

WINGER: My name is Barbara Winger. I'm a staff occupational therapist at St. Margaret Memorial Hospital in Pittsburgh.

Much of the testimony you have heard has presented regional statistics and has spoken in terms of thousands of arthritics. I would like to focus your attention on the problems of delivering direct patient care to the individual with arthritis.

My experience as a staff occupational therapist in an arthritis center has shown me that advancements in research and education are worth little if knowledge does not reach the allied health professionals treating the patient. New knowledge is worth even less if the arthritic cannot be in contact with qualified health personnel or, of course, follow their advice.

Arthritis is a chronic disease requiring periodic reappraisal of the patient's ability to function. As an occupational therapist, I evaluate people's ability to meet their needs and accomplish the tasks that are important to them. The early arthritic may be quite functional and need only advice on techniques to reduce joint strain and conserve energy.



People with more advanced arthritis may require special self-help devices to be independent.

Providing these needed services is difficult due to limitations in manpower, educational resources and funding. Due to shortages of personnel most arthritics will never come in contact with an occupational therapist having expertise in rheumatic disease.

There are an estimated 400,000 persons with some form of arthritis in the western Pennsylvania RMP region. In this same area there are 77 occupational therapists; of these, 9 have special training in arthritis. This gives me a potential caseload of nearly 44,000 patients. Obviously, many arthritics will not receive the services they need to lead more productive lives.

When discussing the patient's functional deficits, I may run into a problem that I cannot solve. If I turn to the professional literature provided, I will find few articles written for the occupational therapist. There are many medical texts written about arthritis, but few provide the practical application the allied health professional needs to help the patient improve his or her daily life. So I will attempt to solve my patient's problem by consulting the only resource I have: my on-the-job experience.

Implementation of solutions is often made more difficult by lack of funding. Much of the education needed by an arthritis patient could be done on an outpatient basis, but third-party support for outpatient treatment will be extremely limited. Any education done outside of an inpatient state will probably not be covered by the patient's insurance. Even Medicare, which is administered by Blue Cross of Western Pennsylvania, will not pay for outpatient occupational therapy outside of a certified home health agency. This lack of support often makes home visits by therapists not working for a home health agency financially impossible to patients.

Self-help devices, such as elevated chairs or adaptive feeding utensils may be all that a patient needs to be independent. None of these are covered by private insurance or by Medicare. This lack of support by the health care system may prevent patients from continuing their hospital programs at home.

I am making the following suggestions in the hope that the Commission will address itself to these problems:

- (1) Instruction in rheumatic diseases should be increased in undergraduate programs for allied health professionals. Provision should be made for short-term courses to reach professionals already in the field.
- (2) Grants must be available to allied health professionals for research and publications to better educate the physicians in their field.

- (3) Existing government health programs should include coverage of outpatient services and self-help devices, or new programs should be established to provide for the chronic medical needs of the arthritis patient.

I request the Commission to consider these suggestions to help ensure that the increased knowledge gained through research will reach the person who needs it the most: the person with arthritis. Thank you.

ENGLEMAN: Thank you. Thank you very much, Ms. Winger. Dr. Viozzi.

TESTIMONY OF  
FRANCIS J. VICZZI, M.D.  
RHEUMATOLOGIST, GEISINGER MEDICAL CENTER  
DANVILLE, PENNSYLVANIA

VIOZZI: I practice with one other rheumatologist, Dr. Randolph C. Blodgett. We practice on the staff of the Geisinger Medical Center, which is a large, closed-staff institution of 120 full-time physicians. Our institution is located in rural north central Pennsylvania, very rural.

We've heard about the problems and thoughts of the city-oriented persons, and I'd like to tell you what rheumatology is like in the hinterland. The referral area we encompass extends from Johnstown on the west to New Jersey on the east, and from near Harrisburg in the south to the New York State line in the north. Our primary service area encompasses 5 counties, and it includes 229,000 persons, but the total referral area is several times larger. Our practices are both strictly limited to rheumatology.

There are no good epidemiologic or population studies of the area which will allow us to determine the number of patients suffering from arthritis and related disorders. Some degree of the magnitude can be easily inferred, however. Dr. Blodgett and I see approximately 50 new patients weekly, all of whom suffer primarily from rheumatological illness, and follow-up visits number about 100 a week. Our senior residents see new patients on an irregular basis.

Despite our total effort, we cannot make any headway. Our waiting lists for new patient evaluations become larger constantly. At present, our new patient lists are full to capacity through January, 1976. By opening our appointment books now, we could fill all of our time for the next calendar year with ease.

We are the only rheumatologists in the referral area. If a patient prefers to see a trained rheumatologist there is no choice other than to travel to Harrisburg, Philadelphia, or Pittsburgh. Obviously, our need for help carries a high priority with us.

Considerable antipathy is directed toward many types of patients with chronic illnesses. The course of the chronic disease is discouraging. Treatment is either bland or fraught with danger, on an equal-time basis, the diseases are not particularly remunerative. The patients with

rheumatologic diseases suffer this antipathy as much or more than anyone. We see grossly suboptimal treatment stemming largely from ignorance of the disease as well as fear of the therapeutic modalities routinely utilized by rheumatologists.

We hope you will recognize that these problems should be met head on by an inspired educational program. And we feel that such a program is again one of the primary needs of our area. A recent program at Geisinger on rheumatoid disease brought over 100 enthusiastic physicians for an entire day program. Acceptance is thus quite high. But we continue to require help. Programs such as this will undoubtedly upgrade the present primitive approach to the care of rheumatological diseases.

We feel strongly that more emphasis should be placed, at the medical school level, on medical student and graduate education. We, of course, strongly support the research effort, but much of it is redundant. Perhaps more emphasis should be placed on training practitioners who would help us with our immense burden of patient care.

It is a particularly morose fact of academic life that several medical schools in this country deem it inadvisable to have departments of rheumatology. Our chapter of the Arthritis Foundation has been impatiently awaiting the birth of such a department at the local M. S. Hershey Medical School. It is a sad fact that a magnificent institution with such outstanding cardiology, hematology, and gastroenterology, and which is allegedly dedicated to training physicians for primary care, consistently neglects to initiate that department which trains physicians to take care of the most common problems with which patients present us.

Our priorities for the needs of this area, from our own selfish standpoint, are as follows:

- (1) Postgraduate educational programs for practicing physicians to upgrade their diagnostic and therapeutic skills.
- (2) Strong emphasis on support for medical students and fellowship training in clinical rheumatology.
- (3) A program encouraging rheumatologists to practice outside huge population centers perhaps by establishment of more arthritis treatment centers in the rural areas. Thank you.

ENGLEMAN: Thank you, Dr. Viozzi. Do you have any thoughts as to how we might improve the fulfillment of educational needs for the primary physician?

VIOZZI: We are doing this through a rather extensive group of programs held at our institution. It's a geographically central area, and we can bring a large number of physicians there. In the three years that I've been at the institution, by having two or three programs on rheumatology per year, we have noticed a rather great upswing in the quality of care that's rendered by primary practitioners. We think this is one very effective method.



ENGLEMAN: Any other questions?

LAWLESS: Just one, Dr. Engleman. In terms of your community, what percentage do you refer back to the general practitioners, and what percentage do you hold on to that could become primary care patients?

VIOZZI: We try to refer them all back for community relations. In reality, those with the most difficult problems stay with us; I would say perhaps 10 to 15 percent. I have no hard figures.

ENGLEMAN: Thank you, Dr. Viozzi. Clivia Stegman.

TESTIMONY OF  
OLIVIA STEGMAN  
PATIENT, MEMBER OF LEANON  
AND THE NATIONAL ORGANIZATION FOR LUPUS

STEGMAN: Thank you. I'm very happy to be here today to speak before the Commission. I was almost in the same situation as the testimony that was presented earlier today. I got out of the hospital Saturday morning, and I thought I wasn't going to be able to get here. I had to travel all night to get here, and, truly, it's been a very inconvenient situation for me, but I felt that it was important for me to come to speak before the Commission today.

It has truly been an educational experience for me as a victim of lupus. I've had lupus for 8 years. And I will deviate to some extent from my testimony and say that the people that are here are really (inaudible). The testimony I've heard has really inspired me because I see some of the people from my own area here, people that I've come in contact with just recently in some cases, but some that I've known for a number of years.

I was a patient at St. Margaret Hospital until recently, and I did become a patient there, but I come here independently of the hospital, just to represent two organizations: Leanon, which is an organization for people with lupus; and the National Organization for Lupus.

I guess most of you would wonder why the National Organization for Lupus was created. Well, arthritic diseases, apparently, seem to be female diseases. I'm female so I'm interested. And when I'm in the hospital, I come in contact with quite a few females with the disease. When I try to find statistics, I find that the statistics show that the victims of these diseases are overwhelmingly female. In some cases, I feel that not enough research is directed towards these diseases because they are female diseases, because I'm a woman and no one seems to care what happens to me.

I think that if these diseases would have affected the military-I've heard businesses say that businesses aren't interested in the disease. Why not? I have to run a home. I have children. These statistics aren't figures where they figure the loss to an economy.

I'm getting very emotional because to me it is an emotional situation. I can't tell you the frustration that I have felt as I've heard some of the testimony. And some of the time I've really wanted to ask my questions of some of these people who were talking.

I'm here in support of what's being done at St. Margaret's. It took me a long time to find out what the story was, but I've realized that the material to educate me isn't available.

When I became a diabetic I was shown a short film telling me how to deal with my diabetes. When I became a victim of lupus all I could find was a short paragraph in a medical book telling me that the prognosis meant death, that the prognosis was death.

Any information is hard to get. I call myself a professional patient, and I try to get information. And most people, if they know something, do tell me. It's not fair. More money has to be directed toward getting some of this information to the patient, and setting up self-help organizations like ours.

When I began to deal with this organization I became involved with and I met other victims of this disease, and I can't tell you how important and how much it changed my life and how I feel organizations like ours are able to change people's lives. Our lupus Pennsylvania chapter has a slogan: "Lupus is not a disease, it's a way of life," because you live your life even though you have the disease and you need supportive help.

I was very happy to see Dr. Ehrlich here because the statement that I had originally wanted to present--he pointed out the important need for counseling and supportive help. And I'm telling you, it's just not there. I've worked with social workers and other people who were supposed to give me counseling and help and they don't know as much about lupus as I do, and that really makes me feel shaky.

When I was in the hospital, every person who would listen to me--nurses aids, anyone--I would give them any information that I had, willingly, with the hope that they would be able to take this information and help somebody with lupus. It's been my gospel. Thank you.

ENGLEMAN: Thank you very much, Ms. Stegman. I gather, then, that you feel that the major thrust of the recommendations of the Commission should be in the field of education. Is that correct?

STEGMAN: Well, I think that all areas have to be dealt with. It shouldn't be an either/or situation. But I want the Commission to know that I do feel that not enough has been done. My primary contention is that not enough has been done because most of the rheumatic diseases appear to be female diseases, and that makes me angry.

It's the same with a disease like sickle cell anemia, which is a black disease. And I know that the education and the information for that disease was not available until a few people started caring and they made other people care. We can't ask people for money to fight these diseases if they don't realize how dangerous and how important they are.

ENGLEMAN: Any other comment or questions from anyone? Oh, sorry. Yes, Doctor?

WHEDON: I just want to express to--we seemed rather quiet in hearing your testimony, but we heard you.

STEGMAN: Thank you.

ENGLEMAN: Yes.

ANTHROP: I think I hear you saying education, patient education. Are you also saying you would like more emphasis on patient counseling as well as patient education?

STEGMAN: Yes. With all arthritic diseases there are problems with depression, and there are other psychological problems that go along with the disease. And I sometimes feel as though people aren't even adequately trained to deal with these problems. I want better trained--I want all these diseases to be dealt with. I want to know for sure that the people are getting the training that they need to help deal with this.

It made me a little bit angry earlier, when I was listening to them talk about nobody wanting to go into rheumatology. I was really angry. Why aren't people interested in this disease? It's been killing people. It's been killing me for years. You know you're all going to eventually die. No one realizes that the disease I have kills. Everybody says, "People don't die of arthritis. They die of lupus," and it's the same disease.

ANTHROP: I know how you feel.

ENGLEMAN: We'll now call on Dr. Burnside.

TESTIMONY OF  
JOHN W. BURNSIDE, M.D.  
DIRECTOR , AMBULATORY SERVICES  
M.S. HERSHEY MEDICAL CENTER

BURNSIDE: Thank you, Dr. Engleman.

I will try to be brief. I am on the faculty of the Hershey Medical Center as Chief of the Division of Internal Medicine, and as Director of Ambulatory Services. And I would like to address the question of why it is so difficult to turn out rheumatologists, and why it is so difficult to teach rheumatological diseases to medical students.

In 1963, Hershey Trust endowed the construction of a medical center with the aid of Milton Hershey funds and presented the campus to the Pennsylvania State University. Hershey Medical Center embraced the principle that modern medical education must be responsible to the health care needs of our nation.



It's rather tragic that that seemed to be a need. This was to be in addition to the time-honored activities of scholarly and inquisitive endeavors not in lieu of them.

It was adjudged important, therefore, to provide an educational system which emphasized patient care endeavors, especially in the fields of primary care. This requires a faculty of scholars who are willing, in large part, to abandon what I call the template theory of medical education, which said, in short, "We will take the best of the students and make them like ourselves. We will crank out professors of medicine and professors of surgery, and we will fill the National Institutes of Health." It meant, instead, that they have to, as faculty members, give the best of themselves to the student population.

To a remarkable extent some of these goals are being achieved at the Hershey Medical Center and at other similar institutions. The faculty of over 200 full-time academicians lend their talents to the training of 350 medical students and in excess of 75 residents for the practice of medicine.

Like all of our medical school colleagues, we have grappled with the concept of core curriculum. The core curriculum is the definition of that body of medical knowledge which every medical student should possess by the time of graduation. The expansion of medical subspecialties, the deluge of medical scientific knowledge, and the increasing demonstration of need by the population, all contribute to making a definition of that core extremely difficult.

Since we have devoted a major share of our energies to the training of practitioners of medicine, it seemed appropriate, and again sadly unique, that we find out something about the health care needs as perceived by our patient population.

An intensive, detailed survey was conducted over our township within which the Medical Center is located. Some 6,000 families were carefully questioned over 4-hour sessions to determine what it was that they perceived were their needs for health care.

Two disease states came out high on top, and they were far in excess of the third, and the two were allergic diseases and arthritis. From this and the national statistics it's clear that we need active programs in arthritis. Most important to institutions like Hershey, every physician needs training in the arthritics. What specialist, pray tell, is not going to be seeing arthritis-related diseases or patients with arthritis in addition to the problem that they might be specifically dealing in?

Because of the numbers of arthritis patients, they are bound to interface with every other specialty in medicine. Clearly, then, training in the pathogenesis treatment and patient education techniques of arthritis management should be a large part of any core curriculum. It is not. And why is it not?

I think there are several reasons: First, traditional basic medical education is organ oriented. Arthritis, with its broad spectrum of

representation and involvement of every organ system, gets a little attention from everyone, but a comprehensive approach from no one.

Second, traditional clinical medical education is oriented to the supine patient. Arthritis care is primarily a specialty of the erect patient and of the ambulatory patient. While many patients with arthritis are hospitalized, the reason for hospitalization is frequently some other time-and thought-consuming problem which preempts due consideration of the arthritis.

Third, arthritis is generally a chronic disease, and gets accorded, therefore, less respect in acute care, center-oriented facilities. Heart disease, cancer, stroke, and the rare esoterica capture the glamour of medical care in the eyes of impressionable students and residents. The enormous personal and economic impact of arthritis is far from their preoccupation.

Fourth, a concept that I like to call "cause and effect delay" in medical education. The greatest learning device for students of medicine is the recognition of cause and effect. When a student or resident who is faced with a sudden and dangerous heart rhythm problem administers an appropriate drug and sees the rhythm restituted to normal, the cause and effect is immediate. His learning experience is enormous. The recognition of cause and effect in the care of arthritis may subsume a time span far in excess of his total training period. The learning experience is therefore less.

Yet, postgraduate education is primarily specialty oriented. The appropriate care of the patient with arthritis requires a sensitive primary physician, but the expertise of a multidisciplinary approach, well elaborated this morning.

To learn about arthritis means to learn what is offered by the rheumatologist, the orthopods, physical therapists, social workers, Arthritis Foundation, and the lay council. Such interfacing of talents in the education of young doctors is extremely difficult to provide on a large scale.

I cannot honestly say that the release of substantial dollar commitments by the government will correct all of these faults. I can't help believing, however, that the traditional assessment of priorities by affixing dollar figures promotes a concept of priorities which is a domino effect. If arthritis were accorded its proper dollar-support figure in relation to its societal cost, we would see the most exciting expansion of its educational programs, and very shortly a major retardation of the cost in human suffering.

One closing remark is perhaps a bit counter to some of the comments this morning about the concept of centers. Lest we destroy a patient by having him confronted with 40 different specialists, all anxious to get a small piece of that individual, let us remember that the electricity and the communication and the real hard line in primary care occurs between the doctor and the patient. If that doctor, whatever his specialty, is

unaware of all of the resources available to him to help his patient, then no center in the world is going to be successful.

The other reservation I have about the center concept is the exclusivity which seems to be promulgated in centers. Most of us trained in traditional medical centers are well aware and remember the specialty clinics--the specialty clinics which were run by a specialist, and their special fellows, and their special residents, and about which dance all of the other specialties, but into which none of them ever dare tread. If that exclusivity is part of an arthritis center, all of your outreach, all of your patient education, all of your triage functions will fail miserably, and I urge you to consider it. Thank you.

ENGLEMAN: Thank you very much, Dr. Burnside. I gather, then, that your major thrust would be in the area of education, professional education?

BURNSIDE: Yes, sir. Education for primary care physicians--all of them.

ENGLEMAN: And research would be of secondary importance?

BURNSIDE: No, no, I would not like to say that, sir. My concept of what the primary care physician of tomorrow needs to be is that he is not just a practitioner, but he's a scholar. He needs to be born and bred, as it were, in an atmosphere of scholarly endeavors, and to acquaint him with all that might be available for the care of his patients it's necessary that he be exposed and be part of scholarly research-oriented endeavors.

ENGLEMAN: Dr. Batchelor.

BATCHELOR: I wonder if Dr. Burnside would take a minute to verify or correct an impression that I've gotten from some of the previous reference to the efforts of his school. Is my impression correct that at the moment there is no one on the staff who is a rheumatologist?

BURNSIDE: That's correct.

BATCHELOR: Is this an area where you see some change, some appointment or--and where does this stand in your priorities, or do you feel that rheumatology, perhaps, can best be made by someone other than? What is the--what goes on there?

BURNSIDE: Bear in mind, if you will, that the Medical Center has been in operation for, just today, 5 years; that no one opens the doors of a medical center with a full faculty; that we are still in an exponential growth phase of the addition of faculty members.

I think, however, it is probably fair to look at the sequence of addition of faculty members to appreciate the list of priorities which may have been established. I would like to remind the Commission that I am speaking on my own, and that I may not represent the views of management. Yes, in point of fact, a rheumatology line item has been designated. We have been interviewing rheumatologists, potential



rheumatologists, for 2 1/2 years. The reluctance is not necessarily that we don't want rheumatologists, we want the very best we can find who will generate scholarly endeavors, education, and patient care.

BATCHELOR: Thank you.

ENGLEMAN: In behalf of the Ccmmission, I want to express our appreciation to all of you who had anything to do with the arrangements of this morning's testimony, and for the magnificent choice you've shown in selecting those witnesses whose testimony today has been very constructive and most helpful. Thank you very much.

Harrisburg, Pennsylvania

October 14, 1975

S U B M I T T E D   S T A T E M E N T S

GERMAINE G. GOTSHALL, R.D.  
Camp Hill, Pennsylvania

October 1, 1975

The Pennsylvania Dietetic Association, representing approximately 1,150 dietitians and nutritionists, endorse the goals of the National Commission on Arthritis and Related Muscular Disease, and thank the Commission for the opportunity to provide the following statement.

We see great need in the area of improving and maintaining the general nutritional well-being of persons afflicted with arthritis and related muscular diseases. The professional expertise of registered dietitians and nutritionists should be used to counsel and guide these persons in the proper selection of foods. In the selection of these foods recognition must be given to the physical limitations of these persons and their ability to open packages, jars, and cans and to cut and chop foods, etc.

A decrease in activity by the person afflicted with arthritis and related muscular diseases may be reflected in a decrease in their appetite or may contribute to a problem with obesity. Therefore interesting meal plans need to be provided that will help to stimulate their appetites without contributing to obesity. For those persons who are obese, dietary counseling should be provided to assist them with weight reduction.

Nutritional counseling needs to assure that the diets of these persons provides sufficient iron intake to prevent the occurrence of any iron deficiency. Other problems related to diet such as diabetes, hyperlipidemia, etc., can best be provided through dietary counseling. Assistance for shopping and budgeting for foods should also be provided. Sound nutritional planning and counseling should also be used to combat food misinformation.

We urge that funds be provided to cover these nutritional services for persons afflicted with arthritis and related muscular diseases.

HANNA GRUEN  
Pittsburgh, Pennsylvania

October 14, 1975

As \* administrator of the largest and only Occupational Therapy Department in western Pennsylvania dealing primarily with rheumatic disease patients, I would like to share with you some of the problems that inhibit good health care delivery.

Adequate staff is a prerequisite to the administration of high level care. Hiring new staff with expertise in rheumatic disease is nearly an impossibility. Those education systems training occupational therapists remain geared to producing generalists. Specific knowledge is, however, required in treating the arthritic patient. The occupational therapist must have awareness of those problems unique to the arthritic in caring for himself. He/she must know of the adaptive equipment available that will enhance the patient's independent function. Hand and wrist

splinting, appropriate exercise, and education for the patient and his family are vital services provided by occupational therapists. Unfortunately, the existing educational process is deficient in these areas. During the didactic process, the student receives only brief mention of arthritis and its devastating effects. One or two lectures by a physician will give the student good insight into pathology and laboratory findings. But additional instruction is needed to give the student practical skills for evaluation and subsequent treatment. Specialized short-term training courses with emphasis on rationale for treatment and direct therapeutic techniques are virtually nonexistent. In western Pennsylvania there is not even a baccalaureate training program for occupational therapists. Consequently, we recruit potential staff from our own students who then reach their level of expertise from on-the-job training. As geographic experts, our staff is called upon to share their knowledge with their colleagues as well as those of other disciplines. The obligation is unquestionable but the ensuing shortage of therapists must limit our ability to care for our own patients. One obvious answer is the availability of a core of allied health professionals who educate others having less expertise. To date, funding for this type of endeavor involving extensive travel is not readily available.

Posthospital care remains an issue for the patient with chronic disease. Two million could conceivably utilize interim home care. Again, lack of trained personnel and lack of funds are the barriers. Recently in attempting to provide some form of occupational therapy for our patients in their own homes, I was able to work out a contractual agreement with the Allegheny County Visiting Nurse Association. One of my staff will provide services for an entire county! Home-care services not under the aegis of a "Home Health Agency" as defined by Medicare cannot obtain coverage by third party payers.

Finally, the physician must be oriented to the services that an allied health professional can offer his patient in order that he might most effectively utilize the limited talent available.

It is my request that the Commission give special consideration to the appropriation of funding for:

- (1) Provision of training programs to develop occupational therapy expertise in the evaluation of patient function, in teaching of joint protection and in splinting.
- (2) Recruitment of graduate occupational therapists for specific training in the treatment of rheumatic disease.
- (3) Provision of follow-up care with interim home visitation.
- (4) Procurement of home self-help devices when no other monies are available.



Harrisburg, Pennsylvania

October 14, 1975

JOYCE CREADY  
Pittsburgh, Pennsylvania

October 2, 1975

Having worked with arthritis patients for eleven years (as a registered nurse) I deeply feel the need for more in-depth education of the public and the patient. I continue to see too many patients who have fallen victim to varied forms of quackery. People need to be informed. We began patient education classes several years ago which was exciting to us (educational too) and all absorbing to patients. They loved it, they wanted to know more. It was their right!

I also encourage the expansion of professional & AHP education programs to attract new interest and better preparation of our professional colleagues working with arthritis victims as well as programs to update those who continue to practice. There are too few really qualified to manage the arthritis patient. Much can be done with your help.

RISA GRANICK, L.P.T., M.Ed.  
Philadelphia, Pennsylvania

October 1, 1975

I am writing to ask your support of Bill HR 14181 to extend services and support in the care of rheumatoid arthritis.

I feel this is an important area, one that afflicts a large portion of our population--both children and adults alike. The care and treatment of these patients is considered so important that increasing classroom hours, in our curriculum, have been devoted to this subject. However, for students and health professionals who are interested in indepth training in a clinical setting, very few hospitals have any formalized program in this area. The University of Pennsylvania affiliates with more than 135 hospitals across the country but less than 5 percent offer any kind of specialized training in collagen diseases or rheumatoid arthritis.

I feel passage of the bill will help hospitals develop programs to:  
(1) serve a greater number of our patient population with this disease;  
and (2) provide more training and research programs for those health professionals interested in specialization in this field.

I hope you will look favorably upon this bill. Thank you.

JEROME L. MARTIN  
Pittsburgh, Pennsylvania

EDUCATION OF ALLIED HEALTH PERSONNEL IN THE  
CARE AND MANAGEMENT OF ARTHRITIS AND  
RELATED MUSCULOSKELETAL DISEASES

Introduction

Allied health personnel are naturally and extensively involved in the care and management of arthritic and related rheumatic diseases. They

provide a valuable and effective source of medical input directly to the patient suffering from the varied affects of arthritis. The role of the allied health professional has been to work as part of the medical team providing treatment to patients to improve the physical and mental well-being.

The problem, however, is that allied health professionals may not view this group of patients and the treatment of them to be a specialty of an area that deserves special training and expertise. In this regard, many allied health professionals who work with these types of patients do not have advanced knowledge or skills that make them truly effective. Those that do have advanced skills are few in number. Therefore, the quality of care from facility to facility may vary greatly.

Another aspect of the role of the allied health professional's input into the management of arthritic patients is that the other medical specialties and the public are not aware of the potential use that could be made of allied health professionals in treating these patients. Physicians, in some cases, do not know how to use other health personnel in helping them to carry out their treatment plan. The public generally is unaware that health professionals, other than physicians, may be able to provide medical care at lower cost and just as effectively.

In view of the large numbers of arthritic patients and the large amounts of money spent both by the public and the government to make medical care available to these patients, there seems to be a need to educate both patients and health professionals, other than physicians, in the management of these patients.

#### Current Educational Status of a Specific Allied Health Professional--Physical Therapists

Physical therapists at the undergraduate level are given basic preparation and knowledge in the approach to arthritic patients. Their training consists of didactic as well as laboratory work in the therapeutic techniques applicable to arthritics. Also, during this time the students are taken to a local hospital (St. Margaret's) where a comprehensive view of treatment with patient demonstration is presented. Also, during the student's clinical education, special projects are arranged for selected students to spend extra time studying the aspects of managing these patients. This clinical education experience is perhaps the only time that actual emphasis or "specialty" training is given to students in this area. In essence, the students are provided a chance to gain a basic understanding of the problems and methods for treating arthritic patients. Little time is spent in going beyond this basic understanding and those that do are few in number.

#### Educational Needs of Allied Health Personnel and the Public

The team approach is obviously important in managing all of the medical aspects of arthritic patients. Some attempt should be made to educate medical personnel, not only physicians, in the medical management of these patients and how each would interact to provide the patient with the most realistic and effective treatment program.

The specific practitioners on the team, physical therapist, occupational therapist, social worker, psychologist, physician, nurse, should be provided with information as to their ideal role in this process and cooperative efforts of all of these people should provide maximum benefits to the patient. This would require advanced education of all of the team members in rheumatic diseases, their problems, management principles, prognosis, and follow-up studies as to the effectiveness of each person's intervention with the patient. Are we really doing the patient any good?

The public, just as the health practitioners, should be educated to the latest medical advances in management of rheumatic disease, the sources of care, and a system developed to make access to these services should be made obvious to the public. Quackery in this area of health is well documented. This aspect alone, if eliminated, would channel many dollars where it could do the most good.

It is suggested that advanced education be given to allied health personnel and the public. The need for increased education of physicians is important, but just that alone would solve only half of the problems. Allied health workers carry the burden of actual treatment. More and better trained people in this area, just as more and better trained physicians, will result in better care. The public needs to "know" about arthritis, all aspects of arthritis.

SUE CARTER, L.P.T.  
Pittsburgh, Pennsylvania

October 14, 1975

The very fact that 20 million Americans are currently experiencing some form of arthritis attests to the need for specially trained health professionals to provide patient care. This training might be attained through various avenues, including undergraduate academic education, postgraduate study, professional schooling, clinical internship, continuing educational seminars or inservice sessions. As a clinical faculty member, my concern lies primarily with the physical therapist. The lack of a basic level of knowledge offered by existing teaching institutions certainly does not insure any minimum level of competent care for the arthritic patient.

Six schools which are representative of physical therapy schools across the United States were queried as to the amount of time allotted to the subject of arthritis including medical lectures, identification of clinical problems and patient management. This time element varied from one hour in one institution to ten hours in another. The others averaged four to five hours of instruction to cover the entire gamut of arthritic conditions and treatment procedures particular to these diagnoses. Mechanics of instruction ranged from lecture material only, presented by general practitioners, to audio-visuals and laboratory workshop sessions. Surprisingly, in only two instances were medical lectures given by rheumatologists.

Clinical internship is a vital element in the educational process of health professionals. Those clinical facilities offering a team



management or comprehensive care approach to the arthritic patient are few, as revealed in reviewing a list of 194 clinical facilities utilized by academic institutions. Of these 194, only 9 offered any programs specifically related to arthritis and to providing students with a more sophisticated level of arthritic management with participation of other allied health personnel.

The six academic institutions also differ in literature they require for reading or that which they provide for students' future reference. Only three of these offer the basic Primer on Rheumatic Disease, published by the American Arthritis Foundation itself.

With the increased use of surgical implants in the arthritic patient has come a new surge of articles in various allied health journals dealing with this subject. However, a review of current journal literature reveals a dearth of articles in consideration of conservative care of the rheumatic disease patient. The same findings hold true for continuing educational seminars.

In summary, it is my feeling that the Commission must, in its allocation of funds and identification of priorities, include some consideration for the training of allied health personnel. Emphasis should be geared to the undergraduate level as well as to providing continuing educational opportunities outside the academic institutions for those already employed in the health care system. These efforts, in effect, would ultimately assure some standard of quality care for those millions of persons afflicted with rheumatic diseases.

LOUISE MOLLINGER, L.P.T.  
Pittsburgh, Pennsylvania

October 14, 1975

As a physical therapist involved over the past five years in the care of persons with the rheumatic diseases, I feel strongly about the need for greater support of all areas concerned in the management of these diseases. With my current position in clinical research, I would like, however, to emphasize my special concerns in this area.

By attending national meetings of health professionals working with rheumatic disease patients, I have become more aware of the clinicians' desires to increase the quality of care provided to their patients. There is an eagerness to share their experiences and learn new techniques. There is also the growing realization that more scientifically sound investigation is needed in order to improve those skills and techniques which we use in our daily contact with patients.

Awareness of the need for clinical research activity to improve patient care in the field of rehabilitation is not new. Over the past ten years, the Journal of the American Physical Therapy Association has exhorted clinicians to become more involved in clinical research. However, in reviewing this journal as well as reviewing the papers presented in the past years at the national meetings of the Allied Health Professions Section of the Arthritis Foundation, little can be found that truly can be called clinical research. More often one finds descriptions

of various techniques and devices or reports of individual experiences in this area. However, these traditional methods developed with collective experience now require more systematic inquiry into their effectiveness. It is only in this way that we can improve the many services now provided to patients with arthritis. In questioning the apparent scarcity of clinical research, one must be reminded of the elements necessary to produce such research: the clinician's time away from the clinic, training in the research process, and financial support of proposed projects. Facilities and clinicians motivated to enter this area of patient care need additional resources which, in most situations, are inaccessible commodities at this time.

Presently, there are only five research fellowships for allied health professionals across the nation all of which are provided by the Arthritis Foundation. Fellowships of this type have the potential to increase the availability of resources needed to evaluate our current treatment techniques.

I would request the Commission's thoughtful consideration of these items and emphasize in their deliberations the need for additional funding in the allied health fields to:

- (1) Stimulate more clinical research among allied health professionals through financial support of proposed projects
- (2) Provide for training in the research process through continuing education programs in the area of the rheumatic diseases.
- (3) Support graduate level educational programs which would allow clinicians to develop expertise in the area of research.

PAUL CONRAD, I.P.T.  
Pittsburgh, Pennsylvania

October 14, 1975

When I came to St. Margaret Memorial Hospital three and a half years ago, I had had two years of physical therapy school and two and a half years of experience.

I felt that I could work with patients afflicted with any disability including arthritis.

Little did I know how minimal my level of knowledge was of the comprehensive management of arthritic patients.

I am still learning new methods and techniques of treatment and getting new ideas after working here three and a half years.

Patients with rheumatoid arthritis have such a complexity of physical and psychosocial problems that they require the combined expertise of all health disciplines.

This includes physicians, both rheumatologists and orthopedists, physical therapists, occupational therapists, social workers, nurses, and vocational counselors.

Without these people working closely together for the achievement of specific patient goals, the patient will

most likely never attain them.

The success of treating a rheumatoid arthritis patient depends upon each member of the health "team" working together but in their own areas of expertise for the total benefit of the patient.

For the past year, I have been serving as a physical therapy consultant to the Western Pennsylvania Arthritis Grant Project.

This program was designed to train allied health professionals in the evaluation and treatment of the arthritic patient.

It is a six-day course that covers all aspects of the comprehensive management of the arthritic patient.

This program has provided me with the opportunity to communicate and work with physical therapists in five different communities in the Pittsburgh area. Prior

to attending this course each physical therapist expressed similar deficiencies in their clinical training and experience:

- (1) inadequate didactic preparation
- (2) inadequate experience in working with arthritis patients
- (3) inadequate short-term continuing education courses for practicing clinicians.

They also expressed an interest in learning more about the following topics if they attended a workshop on arthritis:

- (1) evaluating the patient with arthritis
- (2) presurgical evaluation
- (3) managing the rheumatoid foot
- (4) postoperative management of reconstructive hip surgery
- (5) postoperative management of reconstructive knee surgery
- (6) functional devices commonly needed by patients with arthritis
- (7) orientation to community resources
- (8) decreasing knee flexion contractures in rheumatoid arthritis.

The elimination of all deficiencies would be ideal and best for future physical therapists; however, the most practical approach would be the establishment of more short term training courses for practicing physical therapists to gain knowledge about not only disease processes but also about the evaluation and treatment management of surgical and nonsurgical arthritis patients. I also believe that physical therapy schools need to be made aware of the importance of reassessing current curricula and making appropriate changes in order to alleviate the present deficiencies



as well as to allow for the constant changes that occur in areas such as orthopedics. Then, and only then, if steps are taken to meet these existing deficiencies, will we begin to educate and train physical therapists to better manage the complexity of problems that afflict the arthritic patient.

LOUISE SOLEM  
McLean, Virginia

Mr. Chairman and Members of the National Arthritis Commission:

My name is Louise Solem (Mrs. Joseph A. Solem) from McLean, Virginia. I am an associate member of, and volunteer worker for, the Arthritis and Rheumatism Association of the Washington Metropolitan Area, a chapter of the National Arthritis Foundation. I am also a victim of rheumatoid arthritis and am most regretful that I am, at present, physically unable to give my testimony in person. I appreciate very much the opportunity to testify before you today in my written statement.

When I was asked to submit testimony to this Commission on behalf of Arthritis, Metabolism and Digestive Diseases, my immediate course was to study both The Act (The Enabling Act) Public Law 93-640, 93rd Congress, S.2854, signed into law by President Ford on January 4, 1975, as well as the Hearings on Arthritis Prevention, Treatment, and Rehabilitation, held before the Subcommittee on Public Housing and Environment of the Committee on Interstate and Foreign Commerce, House of Representatives, 93rd Congress, Second Session on H.R. 12150, H.R. 14181, and S.2854 (and on identical bills).

In The Act, my first concern is with Sec. 2, No. (1) under findings, page 1. It states that:

"Arthritis and related musculoskeletal diseases constitute major health problems in the United States in that they afflict more than 20 million Americans and are the greatest single cause of chronic pain and disability."

The facts are, and certainly should be made most clear, that reliable figures from the National Arthritis Foundation, based on the Public Health records of 1969, estimate that there are not 20 million but 50 million Americans, or 25 percent of the population, who suffer from some form of arthritis. There are more than 20 million Americans--1 out of every 10 people or 10 percent of the population, who have arthritis seriously enough to need to be under continuous medical treatment.

It seems important to use the two figures, to make the distinction between them, and to have them spelled out in the wording of The Act to be a total of 50 million, since, both from the economic and medical considerations, 30 million people should not be left uncounted, nor should 30 million arthritis victims be suspended in limbo because, at the present time, we know neither the cause nor the cure, an arthritis patient rarely gets better; his condition worsens and worsens. Except for a rare spontaneous remission in rheumatoid arthritis, the ravages of the disease continue even with treatment. The numerical facts are that:

- 50 million Americans have some form of arthritis
- 20,230,000 need medical supervision
- 3,500,000 are disabled at any one time
- 5 million have the crippling rheumatoid arthritis
- 12 million have osteo
- in addition, 250,000 children have juvenile rheumatoid arthritis
- 600,000 new victims each year
- cost to national economy due to arthritis in wage loss and medical bills is about \$9.2 billion yearly

But note, the true number of all arthritis victims is 50 million, not 20 million. These figures are from the National Arthritis Foundation and I ask that they be included in the record, please.

From previous hearings and study you already are aware that all forms of arthritis are painful--some of them extremely so. Of many kinds of arthritis, the two most common are osteo and rheumatoid. In osteo the patient is usually over 40 years of age, and the joints affected are generally those of the knees and the lumbar and cervical spine. Osteo, which is known as "not the crippling kind" in many cases makes it necessary to replace destroyed joints with artificial joints. Artificial joints are used, also, to replace joints destroyed by rheumatoid arthritis. The artificial joints are frequently rejected by the body, and the joints then fuse.

As for rheumatoid arthritis--which is known as "the crippling kind", the onset is frequently insidious but it may be abrupt, with fever and prostration. Swelling, pain, and tenderness of the joints of fingers, wrists, knees and feet are present. Usually the involvement is symmetrical. The joints are warm, sometimes red, and they contain fluid. Fatigue and weakness usually are present. Pain in the rheumatoid joint is accompanied by splinting of the muscle and muscle spasms. The flexors, the stronger muscle group, are involved and there is flexion deformity as a result. Any joint may be affected, but in the beginning the finger joints, the wrists, and the feet are affected most commonly--then the disease often progresses to the hips, knees, elbows, shoulders, and spine. The severe muscle weakness and atrophy involved are due to pain and the active rheumatoid process in the muscle. It affects not only the joints but destroys cartilage, air space, ligaments, and muscle. It is devastating to the musculoskeletal body system.

It also often affects many of the organs of the body--lungs (with pneumonia a frequent complication), the heart (causing congestive heart failure), the eyes (causing blindness), and the spleen--indeed, no part of the body is safe from its attack. There are more than 2,000 deaths annually attributed to it and to its complications. The rheumatoid pain is excruciating and its devastation can be swift and is incredible.



Rheumatoid victims find the physical and psychological torture, emotional turmoil, and the agony of having to adjust to physical limitations and disability, to be beyond description. Rheumatoid spares no age group; infants, children, adults, any can be seized by it. Rheumatoid can lead to severe crippling, causing many of its victims to become so crippled as to be bedridden.

Arthritis is the oldest disease known--not only in man, but in animals on the earth. Evidence of it is found in the dinosaur skeletons--in the skeleton of a Neanderthal man who lived 50,000 years ago. Interestingly enough, the bones of this arthritic Neanderthal, which were recently found, are said to be the ones of a man of about 40--an old age for that era. He obviously could not fend for himself, but he was apparently kept alive by his companions who tended to his needs. Such compassion among the Neanderthal age may surprise us--and then one asks, why have we waited so long to do all we can for our arthritic compatriots--why have we waited so long to look intently for the cure--and cause--of this disease? How can it be, that in America where polio was conquered and made obsolete by Salk and Sabin--we have done so little, for so long, to try to defeat the scourge of arthritis?

Surely we should make an effort to fund enough monies for the Arthritis Act so that it is possible to mount a crash, massive effort to find the answer to this world-old mystery, to alleviate the suffering of not only America's 50 million but of untold millions on the earth. The drugs used in the attempt to alleviate the terrible destructiveness of this disease are not cures--the destruction goes on and on and on. The drugs are dangerous ones with horrendous side effects, as described by a doctor who testified in the House hearings, they are capable of causing such terrible things as malignancy and, indeed, even death.

The 1974 monies, including those of the government and the National Arthritis Foundation with its constituent chapters, spent on fighting arthritis in this country totaled but \$20 million compared to \$360 million spent similarly on cancer. Yet arthritis is a disease that is second only to heart disease as a cause of disability in this nation. Arthritis frequently destroys not only its victims but the families of its victims--emotionally and economically.

I hope that the Arthritis Act will be funded generously--that in lieu of the usual \$13 million allowed to the National Institute of Arthritis, Metabolism and Digestive Diseases--enough is funded for arthritis to obtain at least \$23 million for this so that this Commission, already set up under Dr. Engleman, already putting into operation its study to recommend major programs that will utilize arthritis funds to their best advantage, will be enabled, as soon as possible to set up the centers and associated programs to combat the diseases.

In 1776 America began an effort that gave the world the right to dream of freedom. In 1976, America could begin the effort that would free the world from the disease which has tortured animal and man from the beginning of time. I hope that, through the hard work of the Commission, it will be possible to fund arthritis research to such an extent that it will be through this country's efforts that the lethal weapon to defeat



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arthritis is forged--that the 50 million American arthritics and their families will be given the thing which they are now without--hope. Faith, they must have--courage, they do muster--but without hope, there is always despair--and hope can come only when word may be broadcast across our land that the research for the arthritis cure has begun in an earnest, organized, united effort that will not fail.

Thank you for your courtesy and consideration.

SENATOR RICHARD S. SCHWEIKER  
Washington, D.C.

October 14, 1975

I am pleased to have this opportunity to contribute to the record of the hearing of the National Commission on Arthritis and Related Musculoskeletal Diseases. As a co-sponsor of the National Arthritis Act of 1974, Public Law 93-640, as well as the ranking minority member of the Senate Health Subcommittee I wish the Commission success in its efforts to develop a long-range plan and recommendations to advance the national attack on arthritis.

Arthritis and rheumatic diseases are second only to heart disease as the most widespread and disabling chronic illnesses in our country today. The annual cost of arthritis and rheumatic diseases to Americans exceeds \$9 billion annually in medical costs, lost wages, disability payments, and taxes lost to the Federal Government. We do not now have the capability to cure, or more important, to prevent, this disease.

Therefore, all Americans look to the leadership of this distinguished Commission and the national arthritis plan it will develop. The plan will include recommendations for the utilization and organization of appropriate national resources in a campaign against arthritis as well as a program to be carried out by the National Institute of Arthritis, Metabolism, and Digestive Diseases, as a major focal point for a concerned attack against arthritis.

As a result of your work, arthritis research will have the potential to proceed, on a national scale, in an orderly fashion under a master plan, pointing out the areas to be pursued, the existing resources with which such activities can be undertaken, and the additional resources which are needed. Also, the plan will provide a targeted approach to reach specified goals.

I am certain the testimony the Commission will hear today will be valuable in focusing its attention on the most worthwhile way to implement this program, and drawing national attention to this important endeavor.

JOHN L. ABRUZZO, M.D.  
Philadelphia, Pennsylvania

During my eighteen years as a physician I have been engaged in multiple aspects of medical practice, medical education, and medical research. These activities have included periods in independent family practice, general internal medicine, rheumatic disease consultation practice, and participation in the Greater Delaware Valley Regional Medical Project Arthritis Control Program. I have been engaged in educational programs at the undergraduate, graduate, and postgraduate levels, including the publication of the major journal of internal medicine, The Annals of Internal Medicine, as assistant editor. I have actively engaged in research in the laboratory and clinical research in the clinic and physician's office. I am drawing on this wide experience to testify to the following deficiencies, problems, and needs.

### DEFICIENCIES, PROBLEMS, AND NEEDS

#### 1. Patient Care

Arthritis care is uneven and deficient largely as a result of the following:

- a. Generally inadequate physician education with regard to arthritis and musculoskeletal diseases;
- b. Poor communication between the appropriate sources of arthritis expertise and most health care providers making key decisions and rendering a specific service.

For example, direct referral of patients from a generalist with usually inadequate knowledge of the arthritic diseases to an orthopedic surgeon for surgery which may be inappropriate or at least untimely. Another example is the failure to provide physical therapy in the presence of a definite existing need for physical therapy and the frequently inappropriate use of physical therapy. Still another example is the frequently inappropriate use and even misuse of drugs for the treatment of arthritis.

#### 2. Education

There are insufficient programs for medical student and allied health student teaching on arthritis and musculoskeletal diseases in many American medical and allied health schools.

On the graduate level, training programs in family practice and internal medicine are too decentralized and lack uniform standards. This is especially pertinent in the area of arthritis and musculoskeletal diseases.

On the postgraduate level, there is the gross lack of any system which ensures that physicians who engage in the management of patients with arthritis and musculoskeletal diseases maintain their competence. This

makes the physician vulnerable to commercial promotional devices. Educational programs in the form of courses are available to physicians, but these are not sufficiently coordinated to fill the need of physician education.

### 3. Research

There is inadequate funding of clinical investigators for studying clinical problems that do not have immediate proprietary and commercial interest. By that I mean there is adequate funding from the pharmaceutical industry to support clinical studies of drugs which are being developed for marketing, but little or no money is available to study already marketed drugs which lack patent protection. There is also inadequate financing of studies of the natural history and clinical and laboratory definition of the arthritis and musculoskeletal diseases. It is my opinion that there is an inadequate volume of more basic research in the laboratory at present. This is due to inadequate volume of more basic research in the laboratory at present. This is due to inadequate support of the training of young scientists who seek a career in laboratory research, lack of support for junior and senior investigators, and finally, insufficient support of the research costs themselves.

## PROPOSALS

Having outlined various deficiencies, I would like to briefly propose:

### 1. Patient Care

Develop on a regional basis teams consisting of health care professionals at all levels. These must include primary care physicians or assistants. The team leader must have all-around arthritis expertise (a rheumatologist would suffice), and all important therapeutic decisions must be approved by him before they can be implemented. It would, thus be highly desirable, if the team leader received no financial gain from any of the alternative modes of therapy.

### 2. Education

- a. Training programs must be developed and supported to a greater extent in the medical schools.
- b. Regional educational programs must be developed which can utilize the same team as mentioned under patient care, but could also be provided by other teams whose primary objective would be education. The latter would lend itself better to procedures for standardization and evaluation.

### 3. Research

Research centers with specific objectives should be developed and supported in order to make thrusts along the research front, but research should also be supported on a broader more individual basis at all medical schools. This helps to bridge the gaps left by the research centers, but more importantly it increases the chances for making a quantum leap. This



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latter development is often the result of an unexpected observation by a fertile and prepared mind.

I believe that my analysis of the problems of patient care, education, and research aspects of arthritis and musculoskeletal diseases is both current and well thought out. I also believe that the few proposals of which I made but brief mention are also reasonable and hope that they will help to form the basis for much needed programs which can be implemented in the near future.

INGA M. BOOK  
Hershey, Pennsylvania

October 1, 1975

As the philanthropic chairman of the Greater Harrisburg Alumnae Chapter of Alpha Omicron Pi Sorority I want to express our chapter's concern for the funding of the National Arthritis Act. There is no need for me to restate the statistics concerning the number of people afflicted and the billions of dollars it costs these people.

We see the major needs to be:

- (1) education of the afflicted, especially in the area of quackery
- (2) more doctors specializing in the care of arthritics
- (3) the establishment of more rheumatology departments in hospitals
- (4) financial help to the afflicted
- (5) and most of all more research to lick this terriblecrippler of so many, even children.

I regret that I will be unable to attend the hearing of your Commission in Harrisburg on October 14, 1975.

Thank you for your kind attention and we do hope that you will recommend funding the National Arthritis Act.

JOHN E. BROWNE LL

Despite the fact that in our Pittsburgh area we have two outstanding centers for research and clinical management of arthritis problems, inadequate financing prevents us from supplying many additional needs for the arthritic patient. These needs are not being met here nor in many other parts of the country, yet arthritis is the nation's number one crippling disease.

Needed are:

- (1) Better education of the public and special training of medical personnel.

- (2) A massive public awareness campaign for physicians and patients.
- (3) Research for better method of control and possible prevention of arthritis. Many patients with arthritis go undiagnosed and untreated for long periods, resulting in permanent and irreversible damage.
- (4) More counseling facilities for arthritics and their families.
- (5) Financing of medical care for people who need it.
- (6) Control over quackery.

Your consideration of these needs will be appreciated.

MARGARET E. KUHN  
Philadelphia, Pennsylvania

Dr. Herbert J. Shulman, Chief of Rheumatology and Geriatric Medicine at Lincoln Hospital and Assistant Professor of Medicine at Albert Einstein College in New York is a friend of mine and a most helpful consultant to the Gray Panthers.

The Gray Panthers are a coalition of people of all ages working together to combat age discrimination and to use the ennergies and experience of old people to work for social change and justice. Health is a priority for our movement.

Dr. Shulman suggested that we testify at the recent hearings sponsored by the National Arthritis Commission in Harrisburg. It was not possible for us to do so in the October hearings. We were wondering if there are further hearings scheduled later this fall? If so, would you please advise me so that we might arrange to have Gray Panthers present testimony.

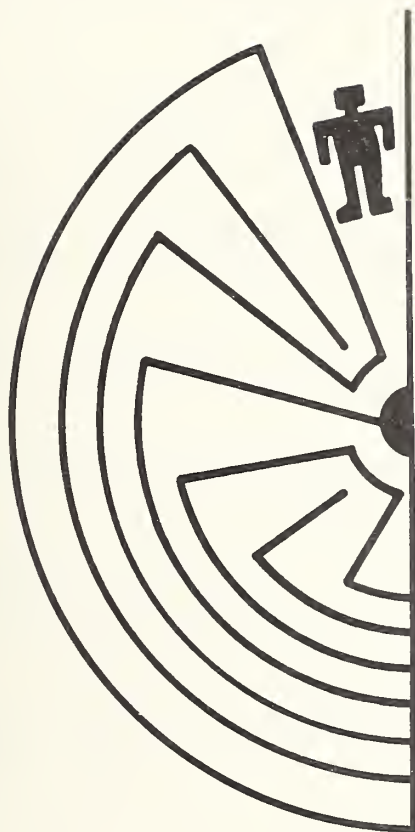
I am a victim of osteoarthritis and have painful knees and crippled hands but I work under a very rigorous schedule and try to deal with the limits of movement as best I can. Dr. Shulman tells me that my hands are classical examples of Heberden's Nodes.

As a movement we are pressing for scme important change in the health delivery system and have stressed the importance of prevention of illness and dysfunction. We also have made an intensive study of nursing homes and organized a group of citizens' advocates who are pressing for nursing home reform.

I look forward to hearing from you and hope that our testimony will be available to the Commission.







**JOHN HANCOCK HALL  
BOSTON, MASSACHUSETTS  
October 15, 1975**



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P R O C E E D I N G S

ENGLEMAN: I want to welcome all of you to these public hearings in behalf of the Arthritis Act.

As you know we have several witnesses who will present testimony. We have so many in fact that it has been necessary to restrict quite rigidly the amount of time we can allot to each witness. We have 4 hours of hearings. We have, I believe the last count was 30 or 31 witnesses, so we must ask you to limit your comments to 4 minutes and this will permit questions from members of the Commission. Again this question and answer session cannot exceed 4 minutes.

We are, of course interested in soliciting information concerning your present situation in the field of arthritis but we are much more concerned with your thoughts and ideas and how your situation can be improved. What are your thoughts concerning the implementation of the National Arthritis Act. By what ways and means can provisions in the Arthritis Act or can our recommendations to Congress in the so called Arthritis Plan help you not only locally but we are of course concerned with the national scene. Now before we start I would like to ask each of the Commissioners to introduce himself quite briefly. I am Eph Engleman. I am a practitioner, a rheumatologist and I am associated with the University of California in San Francisco.

ANTHROP: I am Mrs. Verna Anthrop and from the PIMA reservation and I have been arthritic for 15 years.

AUSTEN: Dr. Frank Austen, Harvard Medical School and Physician-in-Chief of the Robert Brigham Hospital.

BACHELOR: Dr. Bill Bachelor. I am with the National Institute of Arthritis, Metabolism and Digestive Diseases. I am currently serving as Executive Secretary to the Arthritis Commission.

LEWIS: Dr. Vivian Lewis, retired professor of kinesiology and physiology, Central State University, Wilberforce, Ohio.

POLLEY: Dr. Howard Polley, rheumatologist, Rochester, Minnesota.

DONALDSON: Dr. William Donaldson, orthopedic surgeon, Pittsburgh.

SHARP: Dr. Gordon Sharp, rheumatologist, Director of Rheumatology at the University of Missouri, Columbia, Missouri.

JENERICK: Dr. Howard Jenerick, Special Assistant to the Director of the Institute of General Medical Sciences at NIH in Bethesda.

MELICH: Doris Melich, President of the Utah Chapter of the Arthritis Foundation.

SHIELDS: Marvin Shields. I am a physical therapist representing the allied health profession section.



ENGLEMAN: I will ask all persons who appear before the Commission to state their full name, title, and organizational affiliation. As I have already indicated, we must ask you to limit your comments to 4 minutes. We assume that you have a written statement which will be included in a volume which will accompany our report to Congress.

TESTIMONY OF  
KATHARINE PLIMPTON  
PRESIDENT ELECT  
BOSTON CHAPTER, ARTHRITIS FOUNDATION

PLIMPTON: I would like to welcome everybody who is here, and I feel sure that we all have great hopes for the results of this Commission. Perhaps there would be more people here if their physical state of health allowed them to be here.

I am a volunteer at the Robert Brigham Hospital and I am on the board of the Massachusetts Arthritis Foundation. I am also the mother of a child, a boy, who at the age of 13 was diagnosed as having juvenile rheumatoid arthritis. He is now, six years later, a college sophomore. He is majoring in far eastern studies and he is minoring in juggling and riding his unicycle and coeds. We wouldn't, I think, have believed this success of his if you had told us six years ago that he was going to be so well.

In retrospect, I think that there were ways that we could have been helped that weren't available then. In the last couple of weeks when I knew I was going to speak for three minutes here, I called other parents and they also agreed with me that there are significant needs that go unrecognized in the treatment programs of these kids.

I would particularly like to focus on the emotional problems that parents and children have to face in this disease. For a child who is struck down as ours was, one day able to ride his bike, play baseball, etc., the next day sick in bed unable to walk, with a really wild case of the disease. The frustration that he feels when he can't tie his shoes or walk across the room or do any of the things he had been doing is really a very, very difficult problem to face.

I talked with a mother just the other day who has a little boy seven years old, who has been sick all summer. She told me that when he began to feel better about two weeks ago, he got up and he destroyed his room. He threw his toys on the floor; he broke his crayons; he tore up his pictures. He was absolutely wild with frustration. It is almost easier to cope with the apathy that accompanies the flareups of the disease. The hardest thing to cope with is the discouragement you feel when a joint that has been feeling pretty good for a week, is swollen again.

Some kids are ashamed of their illness. When you have been on the soccer team, it is tough to be on crutches or in a wheelchair in front of your friends. It is even tougher to be dependent on your mother. I have discovered that friends of children about this age last about six weeks.

They will keep telephoning or keep coming to their house for about that long and you really can't blame them because there is not much to do.

Arthritis is a lonely disease for parents as well as for kids. I talked with one mother who had to give up her job and stay home to nurse her child.

It is all so frightening. Everyone has known some adult who has been dreadfully crippled by the disease and when you know the name of it, you look into the future and you wonder what is going to happen to your child. One mother told me that she used to wake up at 3 a.m. every morning and lie awake thrashing around worrying about what would happen to her daughter.

In this little book on arthritis -- I wondered whether I was going to be able to say anything that was needful to this Commission. I read this little book on arthritis and Fay C. Lewis says, "If asked whether I think arthritis gets a sufficient amount of psychological attention, I should have to say no. Case records of arthritics are dotted with occurrences which point to unrecognized psychological factors that influence the earlier stages of the disease."

I would like the Commission to consider as part of the plan a program to train therapists-social workers to aid the children in a school-home situation, to help with his fears and his frustrations, to devise programs for the child so that he can be a success at some part of his activities, and to help the parents cope with their fears and their worries. Thank you.

ENGLEMAN: Thank you, Mrs. Plimpton. I gather from your testimony that you would like to put emphasis on the professional education of allied health persons. Is this correct?

PLIMPTON: Yes, of course. Number one, I would like a cure, please. I think we all would. But I am talking about that as being some place in the future, which I know it is going to be. Then I think we could perhaps consider how to help emotional problems.

ENGLEMAN: Any questions from members of the Commission?

MELICH: I was particularly interested in what you said because that happens to be, as the kids say, "my bag" on this Commission. I am very interested in the patient and the patient-family relationship with just such things that you have been encountering and hopefully we will put enough input in this that we will get some reaction.

PLIMPTON: Thank you.

ENGLEMAN: Any other comments, questions? Thank you very much, Mrs. Plimpton.

TESTIMONY OF  
GEORGE KUEHN  
FORMER PRESIDENT OF THE BOARD, ROBERT B. BRIGHAM HOSPITAL  
BOARD OF DIRECTORS, NATIONAL ARTHRITIS FOUNDATION

KUEHN: Mr. Chairman and members of the Arthritis Commission:

My name is George Kuehn and I am a private trustee from Boston. I am here today because of my deep personal interest as an arthritis patient, and as a member of the board of the Robert Brigham Hospital which, as you know, is unique in the arthritis field. I was president of that board for some years when the present format of that hospital was put together. I am also a member of the Board of Directors of the National Arthritis Foundation and of its Executive Committee. I am also chairman of its Professional Education Committee, which brings me to the subject which is mainly on my mind.

All of the new programs for which authority is provided by the National Arthritis Act, especially the proposed establishment of arthritis centers, require more trained manpower at the very outset just to get them off the ground than is now available. The decline in the numbers of trained researchers in the rheumatic diseases relative to the growing need for such personnel has been brought about by drastically reduced levels of Federal funding for postdoctoral training and for institutional support of these activities. The lack of adequate funds is apparent not only in terms of the academic medical specialties in which there are critical shortages, such as rheumatology and orthopedic surgery, but also in regard to the education of primary care physicians who are the backbone of arthritis patient care.

The recent neglect of the need to move biomedical research forward in all areas, not just a few, has exacerbated this critical manpower shortage, necessitating virtually a crash education program as the first phase of the new national effort to conquer arthritis.

The seriousness of this situation has already been recognized by the Arthritis Foundation which, in the past three years, has undertaken two extensive surveys of the manpower needs in the field of the rheumatic diseases. Both of these have dramatically depicted the lack of adequately trained personnel to cope with the gigantic problems caused by these diseases.

I gave this same testimony before the Senate Appropriations Committee in June, emphasizing the fact that in order to implement the program under the National Arthritis Act, the first priority was, and had to be, in the training of new manpower. As I have noted here, the present situation is of declining support of academic rheumatologists, whereas the requirements of this act suddenly accelerate the demand for such people.

Before we can really think about going ahead with the new program, the necessity is to train new academic rheumatologists and orthopedic surgeons. The first priority must be training and, fortunately, the Senate Appropriations Committee took this to heart. In their report they stated that such a priority was necessary--that the National Arthritis Act



would not get off the ground unless the program of education went ahead. I think this is a point that has been established, at least to the extent of getting into an important congressional committee's report, and I submit that as a major thrust for the Commission to follow through.

Now then the question is, if we are so short of trained rheumatologists, academic rheumatologists, where are we going to be able to train new ones? This brings me to a very appropriate topic to discuss in Boston, which is a center of education in the field. There are several great institutions here which you all know have been pioneers and leaders in this field. The Robert Brigham Hospital has been cited as a model center in the Arthritis Act legislation and I think that is an example of the kind of place where this educational effort can take place. The Robert Brigham is a good illustration. The need for education at the hospital was recognized a number of years ago. The hospital, using its own funds, established an academic program which is a very outstanding one. I will not say I think it is the finest one in the country, but you would not be far wrong if you guessed that that is what I meant.

This brings me to the conclusion: My recommendation is that the implementation of the Arthritis Act depends upon a crash program in education of academic rheumatologists. Thank you.

ENGLEMAN: Thank you very much. Any questions from members of the Commission? If not we will proceed to hear from Dr. Sydney Stillman.

TESTIMONY OF  
J. SYDNEY STILLMAN, M.D.  
DIRECTOR OF THE CLINICAL RESEARCH CENTER FOR JRA  
ROBERT B. BRIGHAM HOSPITAL

STILLMAN: I am Dr. Stillman, Director of the Clinical Research Center for Juvenile Rheumatoid Arthritis at the Robert Brigham Hospital. This serious public health problem of the rheumatic diseases has been neglected for far too long and all of us are now agreed that patients with arthritis deserve more effective care. The question is, how can we most efficiently and rapidly provide it? Let us consider some of the factors.

First, patients with the rheumatic diseases should have early accurate diagnosis. Second, they should promptly receive treatment of demonstrative value which is available. This would greatly reduce the disability from the rheumatic diseases. Because over 20 million patients require these services, they must largely be provided by primary physicians. Undergraduate and postgraduate medical education has ill-prepared the primary physicians to deal with the rheumatic diseases.

Correcting the deficiency, training primary physicians and providing more specialists in rheumatology are of prime importance. Existing rheumatic disease centers for teaching, research and patient care must be more adequately supported and others must be established. They not only provide a high level of undergraduate and postgraduate education in the area they serve, but they train specialists in rheumatology who will establish rheumatic disease units in medical schools lacking them and join

inadequately small departments to increase their effectiveness. In nonacademic hospitals, they will care for patients, serve as consultants, teach the resident staff and help to educate the medical profession and public in the area.

Meanwhile, 2,000 rheumatologists must continue to provide specialized care for the more complex problems, serve as consultants and, in addition to their hospital and medical school teaching, conduct courses for practicing physicians. The aim of postgraduate education should be to increase the ability of the primary physician to recognize early those conditions for which he can prescribe effective treatment and also the unusual and difficult problems which require the services of a rheumatologist of the multidisciplinary staff of the center. Thereafter the cooperation and good communication between the primary physician and the rheumatologist will assure the best care for a greater number of patients.

To illustrate some of these points, I should like to discuss a disease which has held my interest since I saw my first case as a student house officer. Juvenile rheumatoid arthritis or familiarly known as JRA. The existence of this disease is not recognized by most lay people and, unfortunately, by many physicians, despite the fact that there are, according to the best figures, about 250,000 cases in the United States. This inflammatory disease of unknown cause begins in childhood but may persist throughout adult life. It can cause crippling arthritis, stunting of growth, life-threatening heart disease and blindness.

Early diagnosis makes it possible to start proper treatment with medicines which can effectively control the disease in approximately 70 percent of the cases, although none should be considered as a cure. In addition, the patients need an exercise program to preserve muscle strength and joint motion. The physical therapist should teach it to the parents as well as to the child. The family will need help in planning the patient's schooling and a regimen which will allow the child as normal and active a life as possible without leading to overfatigue or damage to the joints which can cause the disease to worsen. Families frequently need help, as Mrs. Plimpton said, in coping with the financial, social, and emotional problems which the threatening illness of one child can bring to a family.

Physicians must be more aware that one identifiable subgroup of patients with JRA develops uveitis, a serious inflammation of the eyes which can cause blindness.

My recommendation is to provide the wherewithal for the centers to train more rheumatologists, to start more centers to conduct the education of primary physicians and also to conduct the research which is needed to improve our treatment and complete our work.

ENGLEMAN: Dr. Stillman, I think that in the last four or five years you and some of your associates conducted a survey of the needs for arthritis in the State of Massachusetts.

STILLMAN: Yes, we did.

ENGLEMAN: Would that report be available?

STILLMAN: I would be very glad to make it available to you.

ENGLEMAN: I think it would be very helpful to the Commission. We would like to introduce it into your testimony.

STILLMAN: Very good.

ENGLEMAN: With your permission, of course. Any questions from members of the Commission? Yes, Dr. Sharp.

SHARP: Dr. Stillman, in terms of your recommendation for more support for centers, I wonder if you would now like to elaborate a little bit on that as far as what would be the most efficient way, with the limited funds that will undoubtedly be at hand, to do this?

STILLMAN: I think that there are probably about 45 centers around the United States--some large and some small, but these could certainly be the focus for support, originally to increase their effectiveness in certain instances by making it possible to get to several more rheumatologists or researchers to bring about what they call the critical mass. You have to have a certain number of people in order to be a really effective teaching and research unit, and this is one way that I think we could probably get the most for our money. I think to start in a city where there is absolutely no interest or background or clinic or medical school unit would be rather difficult--to start a large patient care unit with associated research and teaching. They will come, I think, as the program expands, but I think that right now it would be well to start with the centers which are recognized and where rheumatology is presently being investigated and taught.

ENGLEMAN: Any other questions? Thank you very much, Dr. Stillman.

SUBMITTED STATEMENT OF  
SYDNEY STILLMAN, M.D.

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To illustrate some of these points I should like to discuss a disease which has held my interest since I saw my first case as a student house officer -- juvenile rheumatoid arthritis or JRA. The existence of this disease is not recognized by most lay people and many physicians, despite the fact that there are about 250,000 cases in the United States. This inflammatory disease of unknown cause begins in childhood but may persist throughout life. It can cause crippling arthritis, stunting of growth, life-threatening heart disease, and blindness.

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Physicians must be more aware that one identifiable subgroup of patients with JRA develops uveitis, a serious inflammation of the eyes which can cause blindness. Its onset is insidious. In the beginning the eye is not red. There is no pain. There is no noticeable loss of vision. The condition can only be detected by an eye doctor using a slit-lamp. By insisting that every patient in this very susceptible group be examined by an ophthalmologist every 3 months it is possible to detect uveitis early and institute proper treatment. This can reduce the resulting blindness by 50 percent. Further research is needed to eliminate it.

The damage to joints, eyes, and normal development suffered by these young patients will affect the many years of life remaining to them. We must provide them with accurate diagnosis and the best available treatment

now. This will require a major educational effort. Support must be provided for the centers which have the major responsibility for training rheumatologists and teaching medical students and postgraduates. They also carry on the research which we hope will give us better understanding of the rheumatic diseases and their treatment.

I am sure that the patients who testify here this morning will present these needs very clearly and much more dramatically.

REPORT OF THE COMMITTEE ON EVALUATION AND IMPROVEMENT  
OF THE MEDICAL PROGRAM OF THE MASSACHUSETTS CHAPTER  
OF THE ARTHRITIS FOUNDATION

I. INTRODUCTION

On February 1, 1968, the Executive Committee of Medical and Scientific Committee of the Massachusetts Chapter of the Arthritis Foundation agreed that an intensive study of the past and existing medical programs of the chapter be made and that consideration should be given to changing and expanding the medical program so that the needs of arthritic patients in Massachusetts could be more effectively met. A committee was appointed consisting of Dr. Stillman, Chairman, Drs. Krane and Cathcart as members, and Dr. Zeller, Medical Director, and Dr. Stetson and later Dr. Ropes, Chairman of the Medical and Scientific Committee, ex-officio. The committee reported to the whole Medical and Scientific Committee of the Massachusetts Chapter on March 9, 1968. "It was voted that the subcommittee continue its work with the object of developing a plan of study to clarify the goals, objectives, and policies of the chapter and present this, along with a request for financial support, to the Executive Committee for appropriate implementation." On the 19th of March the Budget and Finance Committee sanctioned implementation of the study committee's activities and after some exploration of the matter by Mr. Whalen and Dr. Stillman, Dr. George Cohen of the Massachusetts General Hospital was engaged by the foundation to help the committee conduct this study. Dr. Cohen has met with the committee on several occasions and with its chairman more frequently. On May 5, 1969, he presented his final report on which the committee's report is largely based.

II. SIZE OF THE PROBLEM

The magnitude of the problem of providing care for the arthritics in the Commonwealth of Massachusetts can be stated simply by reporting figures derived from careful studies of the National Center for Health Statistics and the United States Public Health Service. It has been estimated that there are more than 520,000 people suffering from the rheumatic diseases in the state. However, to understand the enormity and complexity of the problem, it is necessary to estimate the number of patients in the 10 population centers in the state and to describe the facilities for their care in each of these areas.

Dr. George Cohen worked with Dr. Theodore Colton in a statistical study of the arthritic population in Massachusetts. They used the "National Health Survey -- 1960-1962," prepared for the National Center for Health Statistics of H.E.W., the 1960 census figures, and the results

of the study in Sudbury, Massachusetts, supported by the United States Public Health Service.

It was felt important to divide the state for purposes of examination. It was deemed advisable to consider as a unit the population in and around a city whose activities formed an integrated social and economic system. The standard Metropolitan Statistical Area, a census bureau classification, was used. This refers to an area which contains one city or twin cities with a combined population of at least 50,000. Contiguous areas are included if they are broadly integrated with the central city in some sense. This arbitrary but useful classification divided the state into the following areas:

Boston  
Brockton  
Fall River  
Fitchburg - Leominster  
Lawrence - Haverhill  
Lowell  
New Bedford  
Pittsfield  
Springfield - Chicoppee - Holyoke  
Worcester

(See Appendix D)

It is conservatively estimated that approximately 120,000 patients in Massachusetts fulfill the strict criteria for the diagnosis of rheumatoid arthritis. The prevalence of rheumatoid arthritis in the 10 major population centers of the Commonwealth and the distribution of patients in regard to sex and age are reported in Appendix B. There are approximately 360,000 individuals in Massachusetts suffering from moderate or severe osteoarthritis.

Extrapolating from the prevalence of gouty-arthritis in a very carefully studied population of 5,000 people, it can be safely assumed that there are approximately 40,000 cases of this disease in the Commonwealth. The estimated number of cases of rheumatoid arthritis, osteoarthritis, and gouty-arthritis is given for each of the 10 population centers in Appendix C. There are no reliable figures for the prevalence of the sixty-odd other diseases which are classified as rheumatic. These diseases do not present as great a problem in numbers, but certainly do in the difficulties they present in their diagnosis and treatment.

### III. EXISTING FACILITIES FOR SPECIALIZED CARE

There are currently 19 active arthritis clinics or centers in Massachusetts. They are:

- (1) Robert Breck Brigham Hospital
- (2) Massachusetts General Hospital
- (3) New England Medical Center



4. Beth Israel Hospital
5. Boston City Hospital
6. University Hospital
7. Carney Hospital
8. Saint Elizabeth's Hospital
9. Lemuel Shattuck Hospital
10. Malden Hospital
11. Lynn Hospital
12. Martha's Vineyard
13. Worcester Memorial Hospital
14. St. Vincent's Hospital in Worcester
15. Holyoke Hospital
16. Lakeville Hospital
17. Springfield Hospital
18. Chelsea Soldier's Home
19. Framingham Union Hospital

This impressive list of clinics needs to be scrutinized. First, it is obvious that there is a markedly uneven distribution throughout the state. Nine of the clinics are in the city of Boston. Four other clinics are located in suburbs of the city which are reasonably closely adjacent. Seven of the clinics are strongly affiliated with the University Medical Center. Most important, it should be noted that 7 of the 10 population centers are not served by an arthritis clinic or center.

The clinics vary greatly in the size and diversity of their staffs, the number of patients seen, the availability of facilities, and the comprehensiveness of their patient care. Seven of the clinics are staffed by only one man. Three clinics are held only when they can be visited by a consultant sent by the Massachusetts Chapter. The clinics or centers associated with medical schools are the best staffed and generally have available to them excellent laboratory facilities, X-ray, diverse consultation services, and the therapeutic services and facilities needed for comprehensive care. The extent and quality of the care varies in the other clinics, both in and out of Boston. In some instances, the clinics are excellent. They are efficiently run and render optimum care. This is not the case in other institutions, however.

#### IV. PATIENT LOAD IN CLINICS

The number of patient visits annually varies widely from 20 in one clinic to nearly 7,000 in another. In the city of Boston, seven of the clinics are very busy but could see more patients. One clinic is working at full capacity and has a waiting list. Two clinics, on the other hand, see relatively few patients in spite of the availability of a well-trained staff.

Almost all of the clinics outside of Boston have the ability and facilities to see greater numbers of patients. Seven of the 10 clinics have actually noted a decrease in the total number of patient visits. This is also true of two of the clinics in the city. It was very disturbing to learn not only that full use was not being made of the specialized facilities available, but that, in some instances, the number of patients was decreasing. This decline in clinic population has occurred since the advent of Medicare and Medicaid and might easily indicate that patients are turning elsewhere for care. Since it has long been recognized that there has been a rather widespread lack of knowledge about the diagnosis and treatment of the rheumatic diseases and, until recently, a lack of interest in them, one cannot help but be concerned about the quality of medical care which these patients now receive.

Dr. Cohen's visits to the clinics of the state and in his discussions with physicians uncovered a serious lack of interest by many physicians in the community to seek help for the care of their patients with arthritis. This seems to stem from many factors. One of the most important may be the fear of giving up any portion of the patient's care and therefore being considered unable to manage a common medical problem. He would thus fear losing face with his patient and the community.

In one moderate sized city there is only one trained rheumatologist to serve the area. He sees very few patients with arthritis in his general medical practice, about the same number as any other internist would. In the arthritis clinic he operates, he sees no more than one new patient during each session. The physicians are reluctant to have a single consultation, whether the patient pays a fee or not. It may well be that in addition to the fear of face or financial loss that the physicians so lack knowledge of the rheumatic diseases that they fail to realize that they may gain by a consultation or at times their patients may be benefited by the specialized care of a trained rheumatologist.

It is noteworthy that even in the larger arthritis centers in Boston and in the private offices of experienced rheumatologists, a large number of the new patients are not referred by physicians in the community but are self-referred or come at the urging of other patients with arthritis. It is important to realize that outside of the city of Boston, there is a very limited number of physicians with specific training and interest in the rheumatic diseases and that only a few of these see a significant number of patients with arthritis.

It is apparent that there are large numbers of patients with arthritis in the state for whom good care is not accessible. Even in regions with functioning clinics of excellent quality it is apparent that there are a

great many patients who could benefit from the expanding volume of specialized knowledge in the field. In Worcester there are at least 5,000 patients with rheumatoid arthritis and in the Springfield-Holyoke area 7 or 8,000. In addition, there are almost four times as many patients suffering from the other rheumatic diseases. It is obvious that the clinics and specialists in the area could not provide care for them all. In 7 of the 10 population centers of the state there are no arthritis clinics and a great lack of physicians with special training and interest in the field of rheumatic disease.

#### V. IMPROVEMENT IN DELIVERY OF PATIENT CARE

The improvement in the quality of patient care cannot be achieved by administering one panacea. Despite the inadequacy of trained physicians and adequate facilities and the incompetence of much of the care which is rendered, the existing clinics and specialists are not being utilized to the maximum. Therefore, it seems likely that the establishment of seven more strategically placed, well-equipped, and well-staffed clinics will not solve the problem. Nine major programs have the support of the Massachusetts chapter. Many of these can be carried on simultaneously, but some will require the successful operation of others. It is apparent that education of the medical profession and the laity is essential for the success of any medical program.

##### A. Postgraduate Education of Practicing Physicians

It must be recognized that it is difficult to attract a busy practicing physician to any form of postgraduate education in a subject in which he had little or no exposure in medical school or hospital training. He must be convinced that he and his patients can be helped by the improved methods of diagnosis and treatment available today and that the field has become much more interesting because of more sophisticated research and methodical clinical investigation which has been carried on in recent years. Lectures, symposiums, and panel discussions in medical societies and staff meetings have some but limited usefulness, but should be offered by the Foundation.

Clinical teaching during a consultation in a clinic or in the wards of the hospital sometimes offers more effective teaching as well as practical benefit to the physician and patient. Physicians should be purposefully invited to attend the grand rounds, ward rounds, and other teaching exercises in the arthritis centers. Postgraduate courses in the rheumatic diseases should be offered since attendance and interest in this type of education has increased markedly in the past few years.

Offering a clinical fellowship in a rheumatic disease center to a selected member of a community hospital with the understanding that he would return there to practice and act as a disseminator of information on the rheumatic diseases offers another method of education which proved successful in the early days of the chapter. Hopefully, an aggressive approach on the part of the chapter would result in 4 or 5 years in an improved attitude of the practicing physicians to learning more about the arthritics so that they could care for their own patients better, so that



they could recognize that they needed further help, and so that they would know where to turn to find it.

#### B. Lay Education

The laity also should be educated so that they do not accept the increasing disability from arthritis as being as inevitable as death and taxes. They should be encouraged to consult their family doctor with the expectation that he would be able to help them or refer them to an individual or an institution where they could get the treatment that they require. If things are not going well, they should know that they can ethically ask their doctor to refer them for specialized care.

The laity should also be educated to a point where they will try to bring to their own communities the facilities and personnel needed to care for the large number of arthritics who will turn up when they realize that something can be done to aid them. Lay groups are interested in lectures and demonstrations. They can be reached through radio, T.V., and newspapers. They should be reminded by all of these means frequently as they have been in the past that the Foundation is prepared to send them helpful booklets and aid in getting the type of medical care they require.

#### C. Education of Medical Students

Medical curricula cannot permit a large block of time to be allocated to a special interest such as the rheumatic diseases. However, if there is within the faculty of the medical school a multidisciplinary group doing basic and clinical research, they can participate in teaching in all levels of the medical school starting with pathology and immunology and moving through physical diagnosis and introduction to clinical medicine and eventually coming to the teaching of the care of a patient with chronic disease, orthopedic surgery, and roentgenology, using material from the rheumatic diseases as the illustrations or examples. If this material is well presented and the curiosity of the students is stimulated, they will elect a voluntary course in their fourth year in the field of rheumatic disease.

#### D. Education of Interns and Residents

The most critical period in medical education in the field of rheumatic diseases comes during the internship and residency. For the first time the newly graduated physician has the responsibility of taking care of patients suffering from the rheumatic diseases. He is fortunate if he has had some preliminary education and developed an interest while in medical school, but in this period in the hospital it is essential that he should have a qualified physician to whom he can turn for good clinical teaching.

This staff member is not only well grounded in the rheumatic diseases but is critically evaluating his experience by doing clinical research or is involved in more basic problems. He will have an even greater chance of catching the resident's interest.

The young physician will realize that the subject is interesting and that much can be done to help the patient who, in an unfavorable setting, is quickly disposed of to a nursing home. It is from this group that the clinical and research fellows come who will be the skilled practitioners, and the teachers and investigators in the coming years.

#### E. Education of Clinical and Research Fellows

It is hoped that the clinical and research fellows will spend at least 1 and preferably 2 years in an arthritis center which is connected with a medical school. Under good direction these fellows can gain wide clinical experience, attend formal teaching sessions, carry out clinical or basic research and prepare themselves for a career in the field of rheumatic diseases.

The clinical fellows who are interested in patient care but wish to continue teaching in connection with their parent institution may serve on the staff of satellite clinics or community hospitals who need a specialist of this type. There they can raise the quality of patient care of arthritics by their practice, their example and their formal and informal teaching. The research fellows prepare themselves for an academic career and at the same time spend sufficient time to become competent clinical rheumatologists. When they leave they should be prepared to do clinical teaching as well as continue their investigative career. In Appendix D an account is given of the subsequent careers of the 58 clinical fellows, the 16 research fellows, the 7 teaching fellows, and the 2 surgical fellows.

#### F. Education in the Allied Health Professions

The Massachusetts chapter has given scholarships to students and grants to their parent institutions for faculty support and other purposes. It is recommended that this be continued and that particular attention be given to the support of clinical teachers in the arthritis centers where the students of nursing, occupational therapy, physical therapy, and social service come for affiliation in clinical training.

#### G. Strengthening Existing Clinics

Medical representatives of the chapter should visit existing clinics to see how they might best help to strengthen them. Providing consultation service to the clinic, a teaching ward visit on occasion to the hospital with which it is connected, provision of needed equipment, the provision of partial support for the physical therapist or anything else which will attract the attention of the physicians in the hospital and the community and influence them to refer patients for care or consultation.

At the Skinner Clinic in the Holyoke Hospital since the late 1950's, 38 physicians in the community have received consultations for their patients with rheumatic diseases. Although some physicians have only sent 1 patient, others have had up to 35 seen. Since the physicians attend the clinic, not only the patients benefited but the physicians, who



undoubtedly were better equipped to deal with similar problems in the future with other patients.

Dr. Cohen found that some of the clinic directors did not realize that they could get partial financial support from the Massachusetts chapter. Some busy clinicians who lacked experience in making out grant applications found the process puzzling and time consuming. Frequently when their grants were returned for revision they became discouraged and did not pursue the matter further. Although it has been made clear that members of the chapter staff would be very happy to help them, they have not sought this help. Visits from the medical staff of the foundation on a friendly basis might be helpful in this regard.

#### H. Support of Arthritis Centers

The Massachusetts chapter is fortunate in having within its boundaries three medical schools with their associated arthritis centers. They have many functions. They provide comprehensive, long term care for patients suffering from the chronic rheumatic diseases. Their professional staffs teach medical students, postgraduate students, clinical fellows, research fellows, members of the allied health profession, and lay groups. They serve on administrative and medical and scientific committees of the chapter, affiliated medical societies and national committees and foundations. They carry on clinical and basic research in the field of rheumatic disease.

They have received support from the Massachusetts chapter and because of their increasing activity in teaching, research, and patient care and also because of the decrease in support from the Federal Government, it appears likely that they will need even further help from the Massachusetts chapter.

#### I. Establishment of New Clinics

In the beginning of this report facts and figures were presented which made it clear that a large number of arthritic patients lived in areas of population density which had no clinics and quite possibly no physicians specially trained in the field of rheumatic disease. However, this section, "The Establishment of New Clinics," was deliberately put at the end of the list of nine recommended programs for the improvement of patient care.

Unless practicing physicians and the laity are aware that something can be done to help the patients with arthritis and desire this help, providing clinics and trained specialists will not bring the patient care to the patients who need it. Furthermore, it is impossible to establish clinics unless trained physicians are available to staff them. Some of the programs of lay and professional education are also dependent on having more specially educated physicians. Hopefully, also this widespread educational program and greater familiarity with the needs of arthritics will make possible the raising of the larger amounts of money which will be required.



Appendix E gives a list of the clinics which have received support from the chapter, the date the support began, and those clinics no longer receiving support from the chapter. It should be noted that only one new clinic has been granted support, the Malden Hospital, in 1965.

#### VI. SUPPORT OF RESEARCH

The Massachusetts chapter's first efforts and funds were quite properly devoted to the improvement of patient care and making it more widely and readily available. They supported the education of clinical fellows to make this possible. They were active in programs of postgraduate education for practicing physicians. They used all means available to educate the public as well. As more funds became available they began to support clinical and later basic research. It is recommended that the clinical and basic research support be continued and also increased. The research activity in the centers is increasing and unless the Federal policy changes, help from this quarter will be difficult to obtain for an indeterminate period.

The Massachusetts chapter did some laudable pioneering in the establishment and development of its medical program. It seemed wise at the end of 20 years to evaluate the problem of helping arthritics in Massachusetts at this time and to try to determine how this best could be accomplished.

Appendix A

## FACT SHEET ON ARTHRITIS AND THE RHEUMATOID DISEASES

Basic Definitions:

Prevalence - the number of clinically active cases observed during a specified time period.

Incidence - the number of new cases whose onset occurred during a specified time period.

Prevalence Estimates of All Forms of Arthritis for United States:

<u>Number</u>	<u>Source</u>
18,074,430 <sup>1</sup>	Arthritis Foundation 1967 Annual Report
13,218,028 <sup>2</sup>	U. S. Public Health Service, 1966
57,000 Juveniles	U. S. Public Health Service, 1966

Groups Most Frequently Afflicted in Rank Order<sup>3</sup> (not mutually exclusive):

- (1) Older People
- (2) Women
- (3) Persons in low income groups
- (4) Residents of rural farm areas

The annual dollar cost of arthritis is estimated to be between 2 and 2-1/2 billion dollars a year. This figure is based on estimates of work loss, disability payments, drugs, hospital, medical costs, etc.

Arthritis is second only to heart disease as the most disabling chronic condition in the United States.<sup>4</sup> More than 14,000 man work years are lost annually in the Northeast Region as a result of arthritis disability.<sup>5</sup> Disability days and activity limitations average more in low than in high income groups -- but lower income families include more older persons than

higher income families. Nevertheless, the rates of arthritis are higher at every age level in the lower income groups.<sup>6</sup>



Appendix BPrevalence Rate for Arthritis and Rheumatism by Region (rank order):<sup>7</sup>

<u>Rank</u>	<u>Region</u>	<u>Rate/1000</u>	<u>Est. Cases</u>
1.	South	94.1	
2.	North Central	88.2	
3.	West	87.1	
4.	Northeast	73.8	3,538,636

Prevalence Rates for Arthritis and Rheumatism by Selected Standard Metropolitan Statistical Areas (SMSA's):

<u>Rank</u>	<u>Region</u>	<u>Rate/1000</u>
1.	San Francisco	77.0
2.	Chicago	71.5
3.	Los Angeles	70.9
4.	Pittsburgh	66.9
5.	New York	60.4
6.	Detroit	59.4
7.	Boston	58.9*
8.	Philadelphia	49.6

\*Boston SMSA has a population base in excess of 2,500,000 and is roughly described by a northernmost point in Topsfield, a westernmost point in Framingham, and a southernmost point in Luxbury.

It is significant to note that there were substantial increases in the prevalence rates for almost every region and area in the 6-year period between 1959 and 1965. Boston SMSA rate increased approximately 45%, i.e., from 40.5/1000 to 58.9/1000. It is not clear to what this rapid rate increase is due, although more efficient case finding, increases in incidence, and longer life expectancy are all likely contributors.

Prevalence of Arthritis and Rheumatism in Massachusetts and Boston SMSA:

Massachusetts -	approximately 322,000
Boston SMSA -	approximately 150,000 <sup>a</sup>
Massachusetts -	approximately 404,000 <sup>a</sup>

Appendix C

Incidence of Rheumatoid Arthritis in Massachusetts Based on Rates Established by Sudbury, Mass. Study.<sup>10</sup>

Average annual incidence - approximately 11,340 cases.

There is 95 percent certainty that the number of new cases of RA will not exceed 23,854/year.

Incidence of Gout in Massachusetts Based on Rates Established by Sudbury, Mass. Study.<sup>11</sup>

Average annual incidence - approximately 3,910 cases.

There is 95 percent certainty that the number of new cases of gout will be no less than 2,346 cases and no more than 5,474 cases per year.

Thus, the average annual incidence for RA and Gout in Massachusetts is c. a. 15,250 cases.

Prevalence Rates for Arthritis and Rheumatism Related to Race:

While the overall rate (nationwide for white persons was slightly higher than that for non-whites, above the age of 45 arthritis strikes non-white persons more heavily than it does white persons.

The date upon which the estimates in this paper are based are basically from two sources; the National Health Survey and the Sudbury Study. It is likely that the estimates based on National Health Survey data are somewhat inflated since self-reporting is the survey data collection method. The Sudbury Study, however, is likely to be more accurate (although it has a serious limitation since it is based on a single, middle class, residential community) as a result of a comprehensive medical examination constituting the data collection process. It will be interesting to compare the estimates derived from Sudbury prevalence estimates (available within the next 4 weeks) and the estimates based on the National Health Survey data.

Prepared by:

Herbert J. Hoffman, Ph.D.  
Heller School  
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March 1969

Appendix D

<u>CITIES</u>	<u>OSTEOARTHRITIS</u> Estimated Total	<u>GOUTY ARTHRITIS</u>
BOSTON	180,000	20,000
BROCKTON	9,900	1,100
FALL RIVER	9,600	1,070
FITCHBURG-LEOMINSTER	5,400	600
LAWRENCE-HAVERHILL	14,400	1,600
LOWELL	10,200	1,130
NEW BEDFORD	11,100	1,230
PITTSFIELD	5,100	550
SPRINGFIELD-CHICOPEE- HOLYOKE	33,000	3,300
WORCESTER	23,100	2,570

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<sup>1</sup>Rate 1/11 - estimated U.S. population, May 1968.

<sup>2</sup>Rate 1/15 - estimated civilian non-institutional population, May 1968.

<sup>3</sup>National Health Survey - 1966.

<sup>4</sup>U. S. Public Health Service - 1963.

<sup>5</sup>National Health Survey - 1967.

<sup>6</sup>U. S. Public Health Service - 1966.

<sup>7</sup>National Health Survey - 1967.

<sup>8</sup>The estimates are based on the rate established for Boston SMSA,  
National Health Survey - 1965.

<sup>9</sup>The estimate is based on the rate established for the Northeast Region,  
National Health Survey - 1965.

<sup>10</sup>Sudbury, Mass. Study - 1966.

<sup>11</sup>Sudbury, Mass. Study - 1966.

<sup>12</sup>National Health Survey - 1967.



ENGLEMAN: Now we will ask Elizabeth Lavertu to introduce herself.

TESTIMONY OF  
ELIZABETH LAVERTU  
PATIENT AT THE ROBERT E. BRIGHAM HOSPITAL

LAVERTU: I am very pleased to be asked to make this statement. My name is Elizabeth Lavertu, and I am a patient at the Robert Brigham Hospital and I have been for the past 21 years.

History

My background is as follows: I am 45 years old and I live at home with my mother, who is 81 years old and she lives on social security.

In 1952, I woke up one morning with a sore finger. This was dismissed by a doctor as "Oh, you have a touch of arthritis." Two and one-half years later every joint in my body was inflamed. At this point, I was sent to the Robert Breck Brigham Hospital in Boston and was diagnosed as having rheumatoid arthritis. This was November of 1955. January 1957, I was readmitted to the Robert Breck Brigham Hospital because of symptom changes. After many tests, I was diagnosed as not only RA, but also systemic lupus erythematosus and polymyositis. I was treated with cortisone. A short time later both the RA and the SLE went into remission, but the polymyositis remained active for many years.

My biggest problem is that of atrophied muscles. I am not able to use my hands or arms and need help with most of my self-care activities; that is, feeding, dressing, bathing. I am able to walk with a specially-built walker.

Social Life

When I first started with RA, I had many friends, but as my condition worsened, I became a drag on their social life. Also my friends married, eventually had children and became involved with their own family life. I then had little in common with them. I now have no social life at all. I require someone with me at all times when I venture out into the world.

Economics

Being unable to work, I am now on a fixed income. I am forced to shop in stores I can get into, so I cannot bargain hunt. I must shop where the ramps are available and the prices are high. The world is not accessible to the person with a walker or a wheelchair. Life insurance companies will not grant me a policy. I did not meet their physical requirements, even though arthritics may live a normal life span. Several years ago I was fortunate enough to get a part-time job working at home for the American Red Cross. I take emergency calls for servicemen and their families when the chapter house is closed. It has been of great benefit to me because I at least feel a part of the world around me. Social security disability is not much help to me, because they restrict me to \$65 per month because I receive supplementary income. This keeps me at

the poverty level. If I make over this amount I loose all my medical benefits.

Biggest Problem

My biggest problem of all is transportation, with a capital T. Since I cannot board a bus, drive a car, or even board a mini-bus, the only transportation available to me is a private taxi, and this is very expensive. My lifestyle could be greatly improved by making some mode of transportation available to me.

Also, my life would be improved by allowing me to earn enough money to raise me out of the poverty level without lowering my medical benefits.

Architectural barriers are a problem. Thousands of dollars could be spent to remodel my home, but there is no financial help available to find a home already built which does not have all these architectural barriers.

ENGLEMAN: Thank you, Miss Lavertu. Your story is all too common in these hearings. Is there any one thing that you would hope that we might be able to accomplish with funding through the Arthritis Act?

LAVERTU: Funding for research.

ENGLEMAN: Funding for research.

LAVERTU: Secondly, would probably be transportation.

ENGLEMAN: Transportation for the patients.

LAVERTU: This is an extremely difficult problem. If there was transportation available for many arthritics we would probably be able to get out and have some sort of social life. As I say, I can't board a public bus; I can't board the new mini-bus that they are talking about, you know, the dial a service buses, or the mini buses. Since I am not in a wheelchair, I don't require, I don't need a medicab sort of thing, but I can get into a car by simply backing up to the seat and sitting down and pulling my legs into it. Many arthritics are in this same situation. They don't need all this special equipment or anything, they just simply need a car that they can back up to; for instance, a four-door car or a station wagon.

ENGLEMAN: Any other questions? Mrs. Anthrop.

ANTHROP: Miss Lavertu, you say that your home has no modifications which would enable you to be more mobile. Have you talked to the local foundation? I know some of the foundations out in the southwest have expended some of their funds in helping modify the home to a certain extent so that the patient could be more mobile.

LAVERTU: I didn't know about this. No, I haven't.

ANTHROP: I think the foundation here would look kindly upon something like that.

LAVERTU: It would be greatly appreciated.

ENGLEMAN: Yes, Mrs. Melich.

MELICH: What kind of help did you get in order to cope with your psychological and emotional problems when you first started into the treatment of arthritis .

LAVERTU: When I first started, I received no help until I went to the Robert Breck Brigham Hospital. My physician is Dr. Sydney Stillman and his philosophy in treating patients is to treat the whole patients. Along with Dr. Stillman's help, I think I was helped through this period.

ENGLEMAN: Thank you very much for appearing, Miss Lavertu. Dr. Steven Krane.

TESTIMONY OF  
STEPHEN KRANE, M.D.  
PROFESSOR, HARVARD MEDICAL SCHOOL  
CHIEF OF ARTHRITIS UNIT, MASSACHUSETTS GENERAL HOSPITAL

KRANE: Dr. Engleman, members of the Commission:

My name is Steven Krane, I am a professor of medicine at Harvard Medical School and Chief of the Arthritis Unit at Massachusetts General Hospital.

Although it may be a surprise to some of you listening here today, we, too, at a large general teaching hospital take care of patients with arthritis. We may even have to take care of patients who have diseases that mimic arthritis in producing pain, inability to move joints and deformities, etc. We see arthritis not only as a specific disorder--perhaps exemplified by rheumatoid arthritis that you have heard about today--but also as a manifestation of systemic disease and as a consequence of trauma.

As a representative of some of the individuals in our hospital who are concerned with arthritis from several points of view, I think it is appropriate to emphasize that we see the problem in two major areas, and we would like to also emphasize again the importance of the general hospital in these problems.

First, we think, comes the application of up-to-date knowledge and techniques in the care of these patients with arthritis and this not only requires physical facilities and drugs but also physician, surgeons, nurses, therapists, social workers and many other professionals, not only requiring the intensive effort of the specialist but also interactions of the generalists to develop diagnostic skills. After all, the proper management in early disease depends upon the recognition of arthritis, and patients with these disorders don't always know what they have, as you have heard already. So we think this is education in rheumatic disease, and we need to support this kind of approach. Also we need to remember that patients with arthritis have nonarthritic complications and some of these involve undergoing orthopedic surgery, a complicated problem, and



often require the backup of the modern hospital which can give special help whenever it is required. I think anyone undergoing a major operation would have to consider this.

I think, however, that an equally important problem is to expand our current knowledge of these disorders. I think we only have to think about poliomyelitis and what the research to isolate the virus and develop a vaccine did to care of polio, and I think most of us should attempt to push our efforts toward similar advances in the arthritis problem. I think that we would like to develop enough efforts to put the Arthritis Commission and ourselves out of business.

We also need to emphasize that there many ways in which this is going to have to occur. I think that there are avenues of approach to diseases that have been emphasized in the report of the hearings I have glanced through, and we have to remember that no one has the monopoly on these approaches, because we don't yet know what the answer is going to be.

We have to continue an approach that would allow for the proper answers for all kinds of arthritis, both osteoarthritis, rheumatoid arthritis, etc., to come. This requires interactions of people from many different areas, disciplines and training in order to have this interaction.

When we think in terms of how the funds could be spent, it is in my mind that research is the major way in which this should be done. We must consider that in large communities, such as Boston, the problems are different from some smaller communities. We are fortunate in Boston to have more than one institution that can take care of patients and do research; yet our emphasis is different, and so I think we would tend to complement each other rather than have any one area that any of us could take over. So I think that the center concept may be one that would involve different people doing different kinds of things in terms of working toward a common goal, rather than to restrict our activities to things that are fashionable that may not necessarily provide the answers. Thank you.

ENGLEMAN: Thank you, Dr. Krane. Any comments, questions from the members of the Commission? Were you about to say something, Dr. Austen?

AUSTEN: No, I would be interested if Dr. Krane would elaborate a little more on the center concept and what he would consider to be the best way for the Commission to proceed in that regard, remembering the legislation.

KRANE: I think this legislation itself, as written, is very broad in its concepts, whereas some of the comments in the testimony, particularly that of Dr. Engleman, gives more restrictive view as to what a center might be. I think it is obvious to many people here that Boston is a center as Boston, because there are at least four or five major institutions, each of which has accomplished things in its own way. I think that a center, then, could provide that kind of idea in which the city might be a center--or a region might be a center--in which there could be some triage, or that kind of phenomenon which would allow patients to get the best of what can be offered in Boston.

I am sure you will hear from Dr. Ewald, but you must realize that there are other people also making advances, and their advances are different. Dr. Mankin's approach, for example, was geared toward osteoarthritis; everybody can't maintain that same approach. Hopefully, we could take advantage of the different kinds of people in a large city to provide the best for patients and to provide the best for arthritis in general. So we might have a city center, or something of that sort. That concept has been used before; it is an old word.

MELICH: I'd like to ask you if you look at a center as a combined sort of work; in other words, research, education and patient care, are you primarily thinking of it in one aspect?

KRANE: No, I think that there are all kinds of arthritis and not only rheumatoid arthritis. It is obvious to everyone here that a great center for rheumatoid arthritis has been at the Robert Brigham Hospital, and it would probably be unwise for us at the Mass General, for example, to make a large effort in that area. We have a relatively small pediatric service and the emphasis on that service is different. So for us this would--not that we wouldn't take care of children as we possibly could--but this might be something that we would best have taken care of elsewhere. On the other hand, there are certain metabolic problems that are occurring and so another institution might have that. So this is what I was thinking of really.

ENGLEMAN: Dr. Sharp.

SHARP: Dr. Krane, given the situation of limited support, would you recommend that this support be concentrated amongst maybe ten major institutions around the country, or would you be happier to divide the support among forty or fifty institutions? How would you deal with regions that are relatively deprived in this country?

KRANE: Well, I think that the major support should be toward research. We want to take care of our patients and I think there are ways in which this could be accomplished. I think that I would favor the distribution of funds to buck up ongoing institutions that already have shown some progress in terms of establishing their own care for arthritis, whether it be in large communities or in small ones, rather than isolate arthritis in a few restricted centers.

SHARP: But would you focus large support in a few institutions or would you try to give a lot to many?

KRANE: No, I would give a lot to many.

ENGLEMAN: Assuming that there was that much available.

KRANE: That's right--in terms of clinical support. In terms of research, I think you have to fund it in the same way that it has been funded in the past. Research has to be competitive and I would hope that it would have to undergo the same kind of peer review that it has undergone in the past. Research was funded on the basis of past

accomplishments and the potential for research in the light of current information is reviewed by experts in the field.

ENGLEMAN: Are you suggesting that such matters as patient care, exemplary patient care, and educational effort should not be surveyed, exposed to peer review and quality control?

KRANE: Why of course it should.

ENGLEMAN: So it goes right across the board, doesn't it?

KRANE: Right, yes.

ENGLEMAN: Not just research?

KRANE: No, of course not.

ENGLEMAN: Right. Dr. Austen.

AUSTEN: Dr. Krane, obviously I agree with the points that you have made. The concept of the city center, or really a "megacenter," introduces the issue of accountability in management and I was wondering to what extent you considered that and examined the option in the Act in the sense--I believe the Act permits special centers which, in a sense, would recognize individual differences in a city such as Boston.

KRANE: Well, obviously there are management problems that would come up. Although we try in medicine, in our days, to be experts in everything; I have tried to avoid being expert in management. However, I think there are individuals who have shown their skills in that regard, and I would hope that they would give us a hand in trying to figure out how we could do that kind of thing. I don't think that the management problems preclude the concept.

SHARP: A different question: There are certainly some very excellent institutions in Boston, and I wonder to what extent you or the other institutions brought your expertise to bear in the state of Massachusetts and is there a statewide arthritis effort going on?

KRANE: Well, I think that we all have attempted to interact both from an investigative point of view--this has been going on for some years--and in teaching and patient care. I think we have done pretty well, and probably a I think it is, I think we have done pretty well, and probably a lot better than other large cities, although it's not ideal. We still are making attempts.

ENGLEMAN: We have time for just one more question. Dr. Polley.

POLLEY: Dr. Krane, I would like to ask you, since we are talking about an area which is well supplied, highly professional, and well developed, what is the major need that Boston has from the Arthritis Act? You may have answered that but I just want to pose it in a different way.



KRANE: Well, I think our major need, as we see it, is some kind of base support for people who are involved in teaching and clinical care. I think that this, to us seems our biggest problem. Even though we are well endowed institutions, the number of people is so great that the amount of money is very little. So we need the kind of support that will maintain full-time people who are able to spend their time teaching and organizing patient care programs for which there is no other funding available that I know of, and I should think this would be the greatest advantage of this kind of act.

LEWIS: To what extent are your medical schools reevaluating their curricular offerings in order that the general practitioner and/or specialist can get more training in the area of rheumatology?

KRANE: Well, we have been reevaluating our curriculum for many years and the curriculum that is involved in rheumatology has been hospital-wide, at least Harvard Medical. The first year we start teaching them about rheumatology, and so they are exposed to it right away. This is my big point, that if you wanted to make any advances in rheumatology you have to expose people who are just growing up in medicine to specialists, and the only place that will be is in the general environment where they start.

So we are very much aware of this and we have been doing it here for many years as a major part of our medical school curriculum in the training of our house officers and postgraduates.

ENGLEMAN: Thank you, Dr. Krane. We will now proceed to hear from Ruth Hirschberg.

TESTIMONY OF  
RUTH HIRSCHBERG  
MEDICAL SOCIAL WORKER, COLUMBIA PRESBYTERIAN HOSPITAL

HIRSCHBERG: Good morning, Dr. Engleman and Commissioners. My name is Ruth Hirschberg. I am a medical social worker at Columbia Presbyterian Hospital in New York City. I am responsible, solely responsible for social services for all our arthritis patients in the hospital and for those who come on an outpatient basis.

Arthritis and its related diseases do not effect merely the joints and other systems of the body but the patient as a total being. As his ability to ambulate or to grasp is decreased, his image of himself and his expectations and goals for himself undergo drastic changes. He mourns his losses and, all too frequently, abdicates his role as a functioning human being. He thus becomes financially dependent on his community, a destructive end result for the individual as well as a constant drain on public funds.

The passage of the National Arthritis Act provides an excellent opportunity to develop a total program to deal more effectively with the multiple needs of the arthritis patient. As the physician begins his diagnostic work up and the formulation of a medical treatment plan, a team

of allied health professionals should simultaneously be making assessments in their own areas of expertise. The social worker is an integral part of this team. By her intervention early on in the patient's treatment, she can institute corrective measures; for example, vocational training and re-employment, housing arrangements, home health services, family counseling, transportation arrangement, prevention of isolation through the creation of groups encouragement to follow through on medical recommendations, ongoing support in rebuilding a damaged ego to strengthen independence and continued productivity.

Chronically ill people represent an enormous drain on our country's resources. Nursing home costs are astronomical, and our cities are faltering under the strain of meeting public assistance payments. Most members of society would rather make it on their own and retain their dignity and usefulness. Help must be available to them at a time when they are least able to cope with appropriate and viable alternatives to chose from. The social worker is trained to offer this constructive help. I should like to recommend most strongly to this commission that social work services be included in all programs now under consideration as an essential component in offering total patient care. Thank you.

ENGLEMAN: Thank you, Miss Hirschberg. Yes, Mr. Shields.

SHIELDS: Regarding the use of medical social workers, is it your feeling that, as they are trained in their basic educational programs they are equipped to work with the arthritis patient or do they require special training? What is your feeling regarding that?

HIRSCHBERG: Well, actually, social work training is rather generic. One is not trained to work in cardiovascular or arthritis or even medical social work. The training is for a helping professional who then adapts and learns on the job. However, I would recommend that if educational funds could become available so that, for example, scholarships could be offered to a second year social work student on the master's level to get field placement training within a rheumatology service there would then be some committment for him, after he gets his master's degree in social work to want to return to this field. We could develop a group of professionals who, as I said before, would be committed to this area rather than being placed in any one of a number of services within a hospital.

ENGLEMAN: Yes, Miss Anthrop.

ANTHROP: I would like to ask ycu how you would motivate some social workers to go in the direction that ycu are working?

HIRSCHBERG: Well, I guess, one of the ways would be to offer financial assistance while they are in their training period, as I have just mentioned, so that once they become exposed to the area they would feel close to people. I personally found, and I have been working with arthritis patients solely for the past eight years that one becomes tremendously attached in this area and knowledge after a while, so you become really much more effective as even a nonmedical professional when you know a little more about the field. I don't think it should be too

hard to motivate social workers. They have a tremendous need to give; this is a good area for it.

ANTHROP: I wish they were all like you.

HIRSCHBERG: Thank you.

ENGLEMAN: Thank you Miss Hirschberg. We will now call on Dr. Ewald.

TESTIMONY OF  
FREDERICK C. EWALD, M.D.  
SURGEON, ROBERT BRIGHAM HOSPITAL

EWALD: Mr. Chairman, members of the Commission:

My name is Frederick Ewald and I am a surgeon at the Robert Brigham Hospital.

The patient suffering from arthritis or diseases causing inflammation and destruction of joints is best treated, in my opinion, in a center devoted exclusively to the diagnosis, treatment and research at all levels of arthritis. This multidisciplinary approach is absolutely essential, I feel, and it should include physiotherapy, occupational therapy, social service, internal medicine or rheumatology, orthopedic surgery, radiology, anesthesia, pathology and other specialty consultants in addition to the usual nursing, dietary, and administrative services found in an accredited general care hospitals. The physical plant of such an ideal center should be small with 120 to 150 inpatient hospital beds equally divided between medicine and surgery with four to six operating rooms and a 24-hour postoperative recovery room.

An adjacent outpatient department however, should be large with a well equipped and staffed outpatient department, the patients can be interviewed, examined, educated and screened and inpatient admissions greatly reduced. The outpatient department would require physical and occupational therapy, social and nursing services and an outpatient operating room and X-ray department. Consultants from the other medical and surgical subspecialties would also have to be available. The outpatient department would be a major part of the training programs for nurses, medical students, residents and clinical fellows.

Basic research into the cause and treatment of arthritis should be an inhouse function at such a center and there should be full-time clinical and laboratory investigators administering these programs. This would maximize patient benefit and make the investigations much more efficient.

Turning to my specific area in the treatment of the arthritic patient, joint replacement surgery, there have been tremendous advances in this field within the past fifteen years. We are now able to replace every major joint in the body after complete destruction by arthritis. With a fifteen-year follow-up from the European total hip experience combined with the hundreds of thousands of patients who have been helped, it is



reasonable to assume that the materials and designs have been proven clinically.

Is there anything more to be done? It would be easy to sit on these successes and reason that perfection is impossible. However, for a very small amount of research effort and funding, large returns can be expected in direct patient treatment benefit. It is because of the large experience behind us that we know precisely what to look at and study for improvement in patient treatment and therapeutic results. For instance, materials can be quickly improved because there are a number of better properties that are biocompatible and only need to be bench tested by joint simulators after fabrication of the appropriately designed prosthesis. In addition, design improvements can be quickly evaluated by bench testing. In the past, the patient was the test machine and some of the early cases resulted in preventable therapeutic misadventures. We desperately need the heap of our engineering college in this area. This pretesting of prosthetic materials and designs also coincides with the government consideration of implant device legislation. Thank you, Mr. Chairman.

ENGLEMAN: Thank you doctor. Dr. Donaldson, do you have a question you would like to ask?

DONALDSON: Well, I think we are all a little taken by the size of your small unit, 125 to 150 beds and if you try to multiply this and design a number of centers that may be available to us over the country, that would seem to favor a very few number of centers of that size. I wonder if that really was your intent.

EWALD: It would certainly be nice to have multiple centers of this size throughout the country. I think what I meant by small size was that the inpatient service should be relatively small compared to the large outpatient department.

DONALDSON: Would you agree that the type of work that you are currently involved in and similar work in design and testing new implants could be done in much smaller units.

EWALD: Yes.

ENGLEMAN: Any other questions? Fine, thank you very much Dr. Ewald. Susan Graetz.

TESTIMONY OF  
SUSAN O. GRAETZ  
NURSE, SLE PATIENT

GRAETZ: Thank you, Dr. Engleman and thank you members of the Commission. I am really glad I got a chance to give my testimony today. It is really super important to me, so thank you.

I am a 23-year-old registered nurse. I am also a victim of one of the most misunderstood diseases of our time, systemic lupus erythematosus. serathemitosus. It first started in February 1974, when I developed swelling in one of my ankles for no apparent reason. I wound up in an emergency room where only a few simple lab tests were done. One of these tests, a sedimentation rate, showed definite inflammation for no real reason. I was then diagnosed as having gouty arthritis and was told to check with my own family doctor. I did so, and no other diagnosis was made by him nor were any other lab tests drawn. So I went my way with only a very low dosage of aspirin for severe pain and a drug called butazolidin to try and see if they couldn't get the sedimentation rate down. I could only take the butazolidin for a short period of time. Instead of getting better with rest, heat and medication; it got worse. It progressed from involvement of only one joint until it seemed that every joint in my body was swollen and stiff. I went to another doctor who gave me a different diagnosis with no lab test to back it up: I want you to remember that. He told me I had rheumatoid arthritis and there was nothing that could be done about it; I'd just have to learn to live with it. The only medication that he prescribed for me was, again, a small dosage of aspirin and valium as a tranquilizer.

I became desperate one night when I got into the bathtub to try to soak my stiff joints. I got in and discovered, much to my dismay, that I couldn't get myself back out. I struggled for a good thirty minutes, each attempt seeming more futile than the one before.

After I did finally get out, I went to the telephone and called my last possible hope, the Robert Breck Brigham Hospital. I had first heard about all the work they were doing there through a television show, "House Call," on which one of the doctors from the Brigham spoke about the treatment of arthritis and said there was something that could be done. It was there that I was finally diagnosed as having SLE and there I was given and have been given, even to this day, more than adequate care and treatment.

In the meantime, I was trying to keep working. I had been working in the intensive care unit; but, due to the disease process, I was barely able to work 24 hours in a week. Even at that I became so tired I could barely eat, and the only thing I wanted to do was sleep. Living alone and trying to be self supporting on this part-time working basis, made it very difficult. I ran out of my allotted sick days in no time. At least I had good medical insurance through work to pay for all those lab tests, drugs, and doctor visits. Now being unemployed, I am no longer covered by the major medical; I have to pay it myself, and I am finding it a little bit difficult.

At first the nursing supervisors were very sympathetic to my problem and they allowed me to transfer to the newborn nursery where they figured the work wouldn't be as heavy. Just the same, I continued to miss great deal of work and I was barely able to keep my head above water. In October the nursery was forced to close and I was transferred to the emergency room, the worst possible place I could have been put. The supervisory personnel felt that the emergency room would be easier to handle because it was different than working on a regular floor. I don't believe they took into consideration the constant stress, the large amount of lifting, pulling, running, cardiopulmonary massage and a supervisor who did not care to try and understand about lupus. She was more than a constant headache to me and pushed me far beyond what my body could tolerate, very often reprimanding me for missing so much work. Even after I tried to explain about lupus, she decided I couldn't work a full five-day schedule and she cut me down to four. I tried to explain that even if I was scheduled to work two days in the week, one of those two days I might have a flare-up with my joints and it would be extremely difficult to move. It was just that unpredictable. But she never took the time to understand.

I finally left the hospital to work in a doctor's office where I encountered a very unpleasant situation. As a result, I am currently unemployed, although looking very hard for some job I would be able to do. My doctors have told me I would be able to do general floor duty if I wanted to wind up with an acute flare-up in two weeks or less. Try to find a job for an R.N. who can't do general floor duty, who doesn't have a bachelor's degree and has a poor attendance record because of her illness at one of the references. It is not easy financially, it is not easy on my person, on my feelings, to be constantly rejected because the employers do not feel that I would be able to do the work that I was trained to do and the only work that I know how to do.

If you tell your prospective employer that you have lupus, they just look at you cross-eyed. It is just an amazed look: "What is that? I have never heard of that."

Also, the jobs I would be capable of doing are grabbed up right away because of the good hours, the less physical work, no shift rotating and, if you have 25 candidates applying for a job, all of them having very similar qualifications and experience, but the 24 others are in good health and you are not, you know who is not going to get the job.

Something has got to be done. Although they contend to hire the handicapped, this is one handicap they can't seem to deal with due to the nature of the disease and the problems surrounding it. Needless to say, one's whole social life is changed. Your leisure time activities are pretty much cancelled; you just don't have the energy to attend them, or you are physically limited in doing them. For example, I used to play several musical instruments, piano, guitar, organ; but with stiff joints you can't get your fingers going or your feet moving fast enough to play them. Because you can't keep up with your so-called social expectations you tend to become very isolated and very much alone, especially when you are in your twenties and everyone else is going out on dates or skiing,



even going to a movie, and you just haven't got the energy to keep up. It gets very lonely.

I don't know how to solve this problem, whether the answer lies in creating a greater awareness and education of the public and those in allied health fields, or whether the lupus patient should just hope for longer remissions or increasing research to find a cure as fast as possible. I am not sure. What I do know, and am keenly aware of, is that lupus creates more problems than just physical manifestations. Because of the general public's poor knowledge and understanding, lupus carries with it great social and economic impact and can bring about many unwanted, undesirable, yet necessary changes in lifestyle. Is there anyone out there who can help? Thank you.

ENGLEMAN: Thank you, Ms. Graetz. Any comments or questions of members of the Commission?

MELICH: I just want you to know that you are not alone. We have a lot of very sympathetic people who understand a lot of your problems.

GRAETZ: It is always nice to know.

ANTHROP: Ms. Graetz, you sound like my case history. I, too, am an R.N., but I was wondering if in your frustrations and your depression period and all that--I know that's hard--but if you could possibly find a clinic, an outpatient clinic to do counseling to other patients, has this ever occurred to you that you, in your situation, may be able to help other patients?

GRAETZ: You mean counseling for lupus patients?

ANTHROP: Right, not only lupus but all arthritic disability diseases.

GRAETZ: That would mean having to go in and out to Boston pretty much, because the hospitals in my area--I live on the north shore--and if they have any really severe cases of people that are having this problem, they are pretty much shipped into Boston for treatment if they are really in an acute phase. But it is a very good idea and I really like it.

ANTHROP: The reason I asked you that, we had another person who gave an eloquent testimony in Washington. She went through the same thing you did and ended up doing that and she finds something in life worth living for now.

GRAETZ: I am kind of getting into that now because I am a volunteer with the Lupus Foundation, so it's coming true.

VOICE: You alluded to the fact that perhaps the nursing profession, while they are one of the allied health people that we certainly would rely on a great deal in helping patients with lupus or with any form of arthritis, but you alluded to the fact that maybe, in their basic training, they are not getting enough time spent on how to deal with the chronically ill patient.

GRAETZ: I was lucky; I went to Mass General for my training and we had heard about systemic lupus erythematosus, so when I was given my diagnosis, I knew a little about the disease; but some of my friends who went to other nursing schools had no idea of how to deal with it. I had no idea about dealing with that. Dealing with the arthritis patient I was fairly limited. I was on a rehab floor at the General and I did get to work a little with them but I was one of the few people who did.

VOICE: So it is, basically, at a center where we have a critical mass of patients a nurse has an opportunity to immediately get acquainted with the disease; otherwise it is-

GRAETZ: Otherwise you really don't. It will be an occasional one.

ENGLEMAN: Thank you, Ms. Graetz. Marjorie Gordon.

TESTIMONY OF  
MARJORIE GORDON  
PRESIDENT, MASSACHUSETTS SLE FOUNDATION

GORDON: Mr. Chairman and members of the Commission:

I think what Ms. Graetz has said makes what I am going to say even more relevant because I come before you in two roles: as the President of the Lupus Erythematosus Foundation and as a patient who also suffers from this baffling form of arthritis. I don't want to speak only for myself but for the 20,000 lupus patients in Massachusetts and for the more than half a million in the country, and I say we need help. We need to be included in any long-range arthritis plan; we feel neglected.

I helped start the Lupus Foundation here in Massachusetts, because I knew only too well what it meant to be ill with a disease that no one had ever heard of and that no one understood. So we ask of you first: Help us create public awareness. There is an appalling lack of knowledge of LE, not only among the general public, but among professionals and paramedicals, as Sue said. Even patients lack understanding. Medical research funds go into other areas, and yet a half a million Americans have LE. Fifty thousand more come down with it each year and at least 5,000 die from it each year.

Researchers have many clues: heredity, genetic defects, environment, immune deficiency; but without funds they cannot go forward nor can they find out why every year there are more cases, nor what the connection is with rheumatoid arthritis or scleroderma.

In our foundation we worry about people like Sue who suffer afraid and alone thinking that maybe they are the only ones so stricken and so misunderstood. As much as the private sector can do, we have taken action; but we and the other groups in the country like us desperately need your help.

We established our foundation over a year ago. We are incorporated under the laws of the Commonwealth of Massachusetts. We are recognized as

a tax-exempt organization by the Internal Revenue Service. But we have found that one of our major problems is that even doctors are not aware of LE and able to recognize it--only the specialists in the large medical centers. We need help in publicizing the symptoms and the problems of lupus. We have even had to set up a counseling service and a referral service to provide psychological assistance, comfort, and solid medical knowledge by experts in the field.

We have found that our biggest job is to inform public opinion so we can mobilize public support and public funds for research. If you can help us, the lupus patients, raise money for research, together we can stimulate scientists to look for and find the causes and cures for LE. Believe me this is not a wild dream. Here in Boston, we have outstanding physicians and researchers who are a part of our foundation and they say that, with funds and support, the answers could be found to this crippling, baffling type of arthritis.

The worst part of LE is that it hits the heart of our population. Its victims are mostly young women in the prime of life, be they students, professionals, workers, or young wives and mothers. Give us the money and give us the help so we can arouse public awareness; so we can help research that lacks funding; so we can stimulate interest and concern in the widespread and devastating impact of lupus erythematosus Thank you.

ENGLEMAN: Thank you very much, Mrs. Gordon. Any comments or questions? Yes, Dr. Batchelor.

BACHELOR: I'd like to respond to some of the points you have made to mention that the research needs and also the special research opportunities in this field have been the subject of a great deal of attention by consultant groups working with the commission. I think Dr. Frank Austen, on my left, has been working most closely with these. Frank, do you want to add to that in any way?

AUSTEN: No, only that is is certainly one of the foremost considerations with one of the so-called cluster groups.

GORDON: If I may just add one thing, out of the first monies that we raised, the first thing we did was give three scholarships to medical students, and I received a letter the other day from one of our researchers which stated that his medical student had definitely been turned on by this research and was continuing in this field and was going to make it his life's work. We feel that is one of the ways we have got to go to work, too.

ENGLEMAN: How would you go about promoting public awareness as you indicated earlier?

GORDON: What we have done here in Boston, with the help of our television and radio stations, is to try somehow to let people hear the word. The average person does not know; I know when I was first told, when a doctor said to me, "You have Systemic lupus erythematosus," I said, "What in the world is that?" And when I have told people over the years that is what I have, that is their answer, too. Somehow you have got to



let people know this is not a strange disease; that many people have it; that it has all sorts of ramifications, all sorts of manifestations.

ENGLEMAN: Thank you very much, Mrs. Gordon.

GORDON: Thank you.

TESTIMONY OF  
JOHN SANDSON, M.D.  
DEAN, BOSTON UNIVERSITY SCHOOL OF MEDICINE

SANDSON: Mr. Chairman, members of the Commission and guests:

I am very pleased to have this opportunity to testify before the National Commission on Arthritis and Related Muscular Diseases. I am one of the few rheumatologists--I note Dr. McEwen on my right--to have had the opportunity to be the dean of a school of medicine. One year ago, when I accepted the Deanship at Boston School of Medicine, I was still active in the clinical practice of arthritis and was involved in research dealing with the immunochemistry of the major components of cartilage.

My comments today will deal primarily with educational needs in arthritis that I hope will be met through the Arthritis Act. I am certain that you have already been told how frequently arthritis occurs and the enormity of the disability and suffering it causes. There is no other group of diseases that causes so many to suffer so long. I am also certain that you have been told that there are many different kinds of arthritis--most are chronic illnesses, but some can be fairly acute and quite pulmonating--and that the cause and cure of most kinds of arthritis are unknown.

The prime educational need is to train additional personnel to render the needed patient care and to make the new breakthroughs that will improve our ability to treat patients with these diseases. Additional monies to support training programs are needed. More clinicians need to be trained. We need more rheumatologists (both in adult and pediatric medicine) more physiatrists and more orthopedists expert in reconstructive surgery. In addition, we need to be certain that all of our primary-care physicians--whether they be family practitioners, general practitioners, general internists, or general pediatricians--be well grounded in the diagnosis and management of arthritis. Most of the medical care given to arthritis patients will be provided by primary-care physicians, not specialists, and And it is essential that they be well trained.

I feel that every school of medicine needs a section, usually in the department of medicine, responsible for teaching all medical students and other health personnel the fundamentals of diagnosis and therapy in rheumatic diseases. Unfortunately--this always amazes me--there are still many medical schools without arthritis programs. This is not the problem in Massachusetts. All four schools have excellent arthritis programs, but they do need additional financial resources if they are to provide all the necessary clinical instruction to medical students, house staff, fellows and other health personnel. Likewise, every evolving program in primary

care needs considerable expertise in arthritis. All too often, this important part of primary care does not receive adequate emphasis. The Arthritis Act should have as one of its goals adequate instruction in arthritis for every medical student in this country.

More researchers also need to be trained. Training needs to go forward in many different areas since we don't know which discipline is going to provide new insights into these diseases. Individuals must be trained in biochemistry, immunology, virology, genetics, clinical pharmacology and many other disciplines. At this point in time, we know only how little we know and how much more remains to be learned. Investigators must be trained and, equally important, then supported so they have an opportunity to create new knowledge and a better understanding of arthritis. Funding to support fellowships and research training programs is critically needed.

The care of many patients with arthritis is really done by a team that--in addition to rheumatologists, physiatrists, and orthopedists--includes physical therapists, occupational therapists, nurses, social workers and others. It is important that adequate numbers of these professionals be trained in arthritis, and that we teach in medical school, in hospitals and in ambulatory settings how members of the team can work together to provide the best total care for the patient.

It is also critical that the importance of patient education be stressed maximally. This can occur in many different ways, but good care mandates that patients understand their disease, their treatment, their disability and the resources available to provide help.

I hope that I have made clear that there is a vast unmet educational need in arthritis. The arthritis act can help meet this need by providing resources to ensure that adequate numbers of clinicians, Allied Health professionals and investigators are trained to care for the millions of people with arthritis, and to make progress towards clarifying our meager understanding of the rheumatic diseases. Thank you.

ENGLEMAN: Dr. Sandson, do I understand that you would make education the first priority?

SANDSON: Well, education in the broadest sense of the work. You have to educate people to be investigators. It all starts with education, and we have to educate patients too. So, to answer your question in the broadest sense of the word, absolutely yes.

ENGLEMAN: Would you put your emphasis on education of young physicians or on researchers?

SANDSON: Well, I think--not to be evasive--I think both have to be educated.

ENGLEMAN: You would divide it about equally?

SANDSON: I really think that there is a need for training programs that will provide physicians that understand this disease or these

diseases, and there is also a need for a training program that will provide people to staff the teaching programs in teaching institutions. There is a need to train investigators; there is a need to train different kinds of personnel, and I hate to prioritize them because they are all important.

ENGLEMAN: Of course they are, but I think somewhere along the line somebody has got to prioritize them. That is one of the dilemmas that we are faced with. Yes, Dr. Sharp.

SHARP: Dr. Sandson, Mr. Kuehn and you have both highlighted the importance training many more physicians and other health professionals. Now, in order to use the monies that might become available under the Arthritis Act most efficiently, how would you pursue training additional rheumatologists and other physicians to lead these programs and new programs to come? How would you accomplish this?

SANDSON: Well, I tried to check my data sources to see just how many schools, medical schools, today don't have a full-time rheumatologist or formal programs in rheumatology, and I don't know whether my data are correct; I think they are off. But I have been told that about a third of the medical schools in this country don't have a full-time rheumatologist on their staff and probably another 10 percent of the schools don't have a formal program in rheumatology. I would almost be willing to assume that in those schools many students finish without adequate training in understanding the fundamentals of the rheumatic diseases. I think some monies need to go into making certain that every school does have at least a minimum training program in arthritis, at least for its students.

Training has to go on at all levels in the medical school--students, house staff, fellows and training for very sophisticated research. If we are going to make real progress in getting more care in arthritis to more people, not only do we have to create new knowledge; but we have to create physicians who can apply that knowledge. I think we have a problem there.

SHARP: We heard yesterday, in a testimony from another institution, that they have tried for three years to establish a rheumatic disease unit; and they have had many difficulties, the chief one of which is manpower--being able to recruit such individuals. So what I am wondering is, assuming there are a third of the institutions in this country that have no program or limited programs, where can we best train this group of individuals who can then provide leadership in the currently lacking institutions?

SANDSON: I also tried to check data on this. There are probably about 27 varied places that have formal training programs in rheumatology which could supply physicians to staff other training programs in medical schools. I think their productivity in manpower would have to increase about 600 percent to meet the needs. So this is one place where we have to start. We have to take the existing places that train rheumatologists and increase their resources so they can train more. I think we are going to have to try to establish more training sites, too, but it is going to have to be sequential.



ENGLEMAN: Dr. Austen.

AUSTEN: John, I think you are in a unique position in the sense of having been both an investigator-rheumatologist and now a dean with very broad responsibilities. So I would like to ask you really two questions: First, you found some difficulty in making a choice between training the investigator and the clinician because we have needs in both. I wonder whether, if you were to reassess the old training programs--where in fact some of the trainees ultimately became primarily clinical and others primarily scientific--what what you would identify as the defects in that system, if any. The second question that I would ask you would relate back to the issue of recruitment. Do you feel that a university, such as your own, in which you of course have a center, can recruit a single rheumatologist; or is it, in fact, necessary to be recruiting a critical mass in order to really offer an attractive opportunity?

SANDSON: Taking the second first, I think it is hard for any one person in any discipline to work in complete isolation, and I think most schools will need a critical mass. It depends on what the goals of the institution are, if they are mainly teaching and training goals, I don't think that critical mass need be very big. I think that it is possible in a medical school to have a teaching and training mission that can be delivered by a small training mass. Looking back at the old fellowship programs--I look back at them fondly--and I think, if wisdom was used in the recruitment of people into the programs, they work beautifully.

I guess the criticism has been that the goals maybe were not fully understood, but theoretically everybody who went into one of those programs was supposed to come out primarily a teacher or an investigator. I am not sure that everybody who went into the program understood that that was what was supposed to happen. I think that the people who were trained in those programs who ended up clinicians have ended up being excellent clinical rheumatologists and those who have ended up investigators have ended up excellent investigators, and some have managed to do both. I think they were very good and I think it probably is a mistake to have the restricted goal that those programs theoretically had and it probably was just as well that the people didn't know what the goal was.

ENGLEMAN: Thank you very much, Dr. Sandson.

TESTIMONY OF  
RICHARD SCHOTT  
REHABILITATION COUNSELOR  
MAINE CHAPTER, ARTHRITIS FOUNDATION

SCHOTT: Mr. Chairman and members of the Commission:

I am a rehabilitation counselor working with the Maine Chapter of the Arthritis Foundation through a grant provided by the Bureau of Rehabilitation. My duties as a rehabilitation counselor include counseling the arthritic sufferer, coordinating medical rehabilitation services and vocational rehabilitation services. As a counselor my goal is to provide the arthritic sufferer as many options as possible concerning the treatment of his arthritis and his employment opportunities. My approach as a counselor is, first of all, to try to counter the physical limitations which he has experienced due to his rheumatic disease. If this is not possible, my approach then becomes that of changing the physical surroundings that he may live in or wish to work in.

In order to assure that every arthritic we meet is presented all the options of treatment for his disease, a process of evaluation has been instituted. The process of evaluation is referred to as the ideal system of care. This system was formulated by the Medical Board of the Arthritis Foundation, composed of three rheumatologists and an orthopedic surgeon. The ideal system of care includes the following:

The counselor, who will utilize this system of care for his clients, requests special consultation from the family physician. The patient is then seen by a rheumatologist who make recommendations toward the medical management of the disease and for further consultation with an orthopedic surgeon or other specialist if indicated. The client or patient is then seen by a physical therapist within his home to determine the physical limitations and in the patients own environment. The patient is also seen by an occupational therapist within the home to determine what specific activities are difficult or impossible to perform. Therapists also note what home modifications or devices will help the patient perform more independently. The counselor's duty is to coordinate all of these services to assure that the patient understands the purpose of seeing each medical specialist and therapist. He makes sure that physical and occupational therapists are available in the area, and--this is the most important part of his duties--he assures that all reports are forwarded to the family or attending physician, since he will provide the primary care for his patient.

This system of care has been utilized in a two-county area in Maine. The results of this system have provided many arthritics with options toward the management of their disease that previously have not been made available to them.

The patient, on many occasions, does not understand the disease that he has and is therefore reluctant to become involved in such a comprehensive system of evaluation and care. The patient at times is

unwilling to follow the recommendations of his own physician due to a lack of quick and positive results and he has limitations.

The recommendations are that counselors, rehabilitation counselors, social workers, any allied health professional that works with arthritics, should be specially trained to work with patients having a rheumatic disease. The counselor should know how this ideal system of care is implemented and be able to coordinate all the services. These counselors would be hired by public or private agencies, that may work with persons having arthritis. Thank you.

ENGLEMAN: Thank you. I think what we may do at this point is go right on to Mr. Kerr. So we will save the questions for later.

TESTIMONY OF  
JARVIS J. KERR  
EXECUTIVE DIRECTOR  
MAINE CHAPTER, ARTHRITIS FOUNDATION

KERR: Thank you, Mr. Chairman. I am Jarvis Kerr, and I am the Executive Director of the Maine Chapter of the Arthritis Foundation. The reason I came to Boston today to share some ideas with you is because the questions you asked were: "What are the most urgent unmet needs?" and "What will the law do about them?" Just across the Merrimac River, the median family income is \$7,746. If you want a quick answer to a longterm solution, provide every arthritis sufferer with a medium income of \$6,000. I don't know who can afford that, because we can identify today that there are 7,880 persons in Maine who are severely disabled, which means they are doing nothing. We have another 9,380 who are so disabled that they can't work, and we have another 10,480 who are working like one of the young ladies was talking about earlier today, with severe discomfort. This comes to a grand total of 27,700 people who need some help today, unfortunately.

Earlier, someone others mentioned research. We need some help today. We need it now. What we have done over the past year with our study that Richard has been leading and the services he has been providing is solving the problem of access and availability. They are really the only two problems that we have in any particular field of endeavor. In Maine, I can report that we now have ten full-time rheumatologists. Eighteen months ago we had one, so the access in Maine has really gone somewhere--excuse me, the availability. Now unfortunately there are about 7,500 patients that don't even know that they are there yet. And I hear the lupus foundation when they say "Hey, let's make some waves."

So maybe I can suggest to your committee not to limit your resources to money, because money is the least amount of strength that I see represented here today. But I can tell you that any one of the physicians on the panel who came to Maine, I could round up 400 physicians to come and meet with you and listen to what you have to tell them about rheumatic diseases.



I am unable to do that in Maine right now. We don't have a Bermuda and we don't have a Fountain Blue or we don't have a nice hotel in the southwest to get the physicians to come to. In fact, we have a need right today of 285 general practitioners because the patient load is around 1,250 to one in the state, average. Now we are a have-not state, if you have heard the terms have and have-not. As a result, we are like the Lupus Foundation is, we are not going to get heard very soon because we have a lot of work to do before we get heard. We only have a million people in comparison to Boston, you could lose them in the north end. So then 7,000 people becomes absolutely insignificant, if you really want to become heartless about the problem, but we think that we need the contact persons trained and that is the people who are out in the field. Most of our work in Maine is done on the outpatient nature as opposed to the inpatient. In fact, only 1,100 in this state last year went to the hospital for arthritis. Out of 7,500 we know that the rest are either self-dosing or going to some outpatient thing or coping.

Now we recognize that the Arthritis Act doesn't give much money when you are talking about the problem on a nationwide basis. But some of the other things that your panel can do and that the Arthritis Foundation is doing, is we try to figure out what our posture is going to be. Is our posture going to be to provide services? We know how expensive that is. We have decided, for at least the meantime, our posture is going to be to monitor good services. When we call a general physician who doesn't know about arthritis, or we have a clue that he might not know--and he can't be expected to know about every major disease entity--we try to tell him what information we want from him. When his patient gets there, we send a set of forms over which is a general physical which is pretty close to what the ARA standards are and say, "Could you please tell us this data?" When we send a physical therapist to the person's house, we give her a series of forms that Robert Breck actually developed and we say, "Fill these forms out and give our Patient Services Committee a look at that patient. The Patient Services Committee is not going to come out to the lady's house. Okay, what good is this? The good is that most physicians see the patient in a nice clean office that is accessible, we hope.

So you send the patient home and say take hot baths. I got a call from Bangor to do that for a lady in that city. All we are asking the Arthritis Foundation to do is to put a tub in her house, so she can take hot baths. Well, we had the house surveyed and they don't have running water, so they are not asking for a tub to be installed now. The lady can't do her physical therapy because she doesn't even have hot water in the tub. In addition, she has three retarded children at home. The husband is working. So it doesn't rain but what it pours in Rustic County, apparently. What I am saying to you is that maybe the recommendations are from my personal perspective.

I want to tell you one bright light. The University of Maine at Farmington is an allied health professional training university, mostly for health education people. We don't have any P.T. training in Maine and the employment projections show that there is only a need for 45 annually to cover a population of a million, when we only have about 175 total physical therapists in the whole state now. We have many less

occupational therapists which we believe are the key and the contact persons, not to forget the nurses.

But the P.T.s and O.T.s and the R.N.s out in the field really need to be trained now and the training needs to be there now. I believe that we have some availability that wasn't even there last year. Now we have got to give the patients access to that, so we have to train the access points, and many of the times the Arthritis Foundation teaches even doctors how to refer. The Arthritis Foundation can do things to the patient that even the doctor cannot do. So even the doctor becomes an access point. Even more important, his clerk or his secretary can refer a patient to the Arthritis Foundation when she notices a need.

Now then, I am saying, if you want to talk about money, my perception is that we need about \$200,000 a year for ten years to make enough of an impact on arthritis in Maine to make it worthwhile. Now I am not saying that has to come from the Commission and this talks again about some of your strengths. To take the money you have and use it as leverage and your knowledge and your power and your insights may be much more important than the 50 million dollars or whatever that is. And then drawing on the strengths of the 75 chapters and others who are interested in arthritis throughout the country, you are talking about a terrifically powerful force. So some of your money probably should go to getting other people to pay their fair share, and you are probably well aware of the 1975 Rehabilitation Act. That money will not come out of the patient, it will not come out of the social security system, it will come out of some other pocket. So we need your strength and your, kind of like the up part of the hammer on the physicians to listen to us from down below and, as much as we need money, we really need them to listen to you who are the experts in the field. If you want to talk about money, the Arthritis Foundation feels that \$200,000 a year for ten years would impact the arthritis problem in Maine. When you talk about your posture, the question you must ask yourself is: Are you going to monitor good services, or are you going to provide services, and that will sort of allow you to choose which way you are going to spend your funds. Thank you for your time.

ENGLEMAN: Any questions from the members of the Commission? Dr. Batchelor.

BATCHELOR: I would welcome some additional comment from the speakers along the following lines. One of the specifications in the act, one of the elements in our report, is to give some attention to existing structure at the state and local level that contribute in some way to the problems of the kind you have described. I am thinking particularly of your request, and it makes good sense to me, that with limited funds coming through this Act that something could be done to stimulate--it can't do the whole job. Could you just pick up this theme and indicate where in your state there are resources that, for example, can match the rehabilitation grant that enables Mr. Schott to do his program, or is that something that is entirely isolated?

KERR: No sir, it is not. First, let me say this: Maine is the first state in the union, we believe, to have a state arthritis act. We are working on it. We need your help there also, because the legislators are



saying to us, "Why do we need a state arthritis act?" We are saying, "Because we would like to be able to have a mechanism to channel what you decide, what you want to do with your money directly to the sufferers." So one area we are working in is the legislative area. If you do, of course, you do it on the national level. The other thing is, with Mr. Schott's project we have found \$3 for every dollar we have spent of rehab money out there. People tend to be insured in Maine. We have a lot of retired persons. Half of our case load is over 65, and we found at least \$3.

Last night we made a presentation to the United Wives and told them that they need our idealist system of care in Cumberland County as well as Lincoln and Saginaw County. We got their attention. We talked about matching type monies. There are several national foundations that should be approached; McDonald Hamburger is one small example. They help other agencies such as ours. But I think even more--I am sorry to be such a grassroots person even though I come from the Catskill Mountains in New York--but I think we have got to get fired up and forget about being defensive about the disease and forget about the past and forget about the quackery accusations and all that jazz and let's get on with it and say you have got some beautiful ARA guidelines for medical management in the office. We are taking those and we are translating them to the social work guidelines, nursing guidelines, physical therapy guidelines. In addition to that, we take Mr. Hollander's "Arthritis Handbook" and ask the patients to ask their physicians if they have got a copy on their shelf. If they don't, they may not be getting the best medical management. This all amounts to accountability up and down the line.

ENGLEMAN: May I ask, are there any components of the state health authority that reinforces in anyway what you are trying to do?

KERR: Just the Bureau of Rehabilitation, at this point.

ENGLEMAN: Could we have included in your written testimony the reference to the efforts regarding the Maine State Arthritis Act?

If you had a draft of that act for example, we would appreciate it very much having-

KERR: I sent one copy to the west coast, where it was

ENGLEMAN: West Coast? Where on the West Coast?

KERR: Wherever Mr. Wartofsky's office is.

ENGLEMAN: Wartofsky, yes, fine. Well then I am sure that will be included in the testimony. Yes.

VOICE: One of the concerns that I have is in regard to finding documentation for your "ideal system of care." I think we have heard a lot about the multidisciplinary approach to treatment and we very badly need documentation that this system, or your ideal system of care is better than any of the other systems, so is there any evidence that people who have received "multidisciplinary approach to treatment" really do stay on the job longer than those who don't? Do you have this kind of documentation and can it be made available to us?



KERR: Right. Again, discussing a little about the actual grant and the purpose of this grant in my position as a vocational rehabilitation counselor, was to provide an evaluation system to be utilized by the state of Maine Bureau of Rehabilitation to determine eligibility and service delivery system to persons having rheumatic diseases. So our first step was to, first of all, find out exactly what is a rheumatic disease, I know two years ago arthritis in my mind, like I am sure many other people's minds, you know, is my grandmother. So and in formulating the ideal system of care, what we wished to do was to have every person that we have as a client, no matter what age or no matter what stage of the disease they might be in, go through the same exact ideal system of care. All of them see a rheumatologist no matter what the diagnosis from the family physician is. If it is any type of rheumatic disease then they automatically are scheduled to see a rheumatologist and a physical therapist. In terms of your question, the documentation comes from what were the results of seeing the O.T., the P.T. and the rheumatologist and in coordinating that to exactly what area or what stage he was in his disease.

We see that some persons who are diagnosed as having osteoarthritis involving only their hands benefit very little from a rheumatological consultation. It was just a matter of documenting or reinforcing what the family physician had said, but, in many cases, we see a rheumatoid arthritic history of ten to 15 years on a medical management of, say, aspirin and no other options have been presented to this person.

In two or three cases we have proved the ideal system of care. Seeing a rheumatologist, which he had not seen in ten years, resulted in a consultation with an orthopedic surgeon which resulted in this man who has had this disease for fifteen years, having a bilateral total hip replacements and bilateral feet surgery. He is scheduled for bilateral hand surgery and the man is walking for the first time without assistance. But we are not saying that that is an isolated incident. We are saying that that is a dramatic change for a person, but we are also saying, for many arthritics that are out there, this may mean the utilization of therapy or the utilization of other medications than what they are on. We go on the assumption that there is always something that can be done to treat the symptoms of arthritis. We are not going to cure it, but a person should not have to be in pain with it.

ENGLEMAN: Mr. Kerr, might I suggest that if you have been developing a report to document your accomplishment under this grant, again I think this would be a very helpful addition to your testimony for the Commission's records.

KERR: Right, we are drawing up primarily two reports coming from my position. One of them is the direct relationship of vocational counselors working in the area of rheumatic diseases on exactly how as a nonmedical person they can implement a very medical system of care. Also, we are documenting the report of the availability of these resources in the state of Maine and how, if there is say a lack of occupational therapists in northern Aroostook County, and there are very few of them, what specific training could you give an R.N. or a physical therapist to fulfill the requirements of an occupational therapist, to cover all of these different

segments of the ideal system of care and showing how even in the northern Arusta County this system can be implemented.

ENGLEMAN: I think even preliminary drafting in this area could be a great help to us.

KERR: Yes, sir.

ENGLEMAN: I would like now to call on Dr. Currier McEwen.

TESTIMONY OF  
CURRIER MCEWEN, M.D.  
CHAIRMAN, ARTHRITIS FOUNDATION'S COMMISSION  
ON CLINICAL RESEARCH GRANTS

MCEWEN: Dr. Engleman, members of the Commission:

I want first to say how much I appreciate the opportunity to meet with you like this and I would like to use this opportunity to talk with you about two subjects. The first concerns general principles about centers and the second, some specifics about Maine.

To establish myself as perhaps qualified to speak on the first subject, let me say that my name is Currier McEwen. I was founder and, for 35 years, chairman of a large rheumatic disease center in an urban university, namely the Rheumatic Disease and Study Group at New York University. I was a member of the National Advisory Council of the NIAMDD in its formative years and for four years I was chairman of its Program Project Committee. More recently I have had the opportunity to be chairman of the Arthritis Foundation's committee on clinical research center grants. I had not thought of mentioning the fact that I was a dean-I didn't think it was particularly relevant-but, in view of the fact that both Dr. Austen and Dr. Sampson thought so, I will mention it too.

This experience that I have had has given me some knowledge of the detailed operations of a rheumatic disease center, and has also provided an opportunity for me to see centers throughout this country. On the basis of that experience, it leaves me with no doubt whatsoever that the most effective way in which the funds provided by the act can be used to help in relation to centers is to give support to existing centers rather than to try perhaps to establish one or two "supercenters". I am sure that there would be little disagreement with that.

Now, I believe that all of the centers throughout the country naturally should differ and do. However, they all should have a base of research, clinical teaching and patient care. They all certainly should differ and will differ, but I believe that, from the standpoint of patient care, there are five aspects which they must have in common: the first is a dedicated, experienced staff; the second is facilities for outpatient care; thirdly, the acute ward type beds for the care of the patient who needs intensive study; fourthly, other beds for the continuing care of the patient; and, finally, some sort of monitoring system so that the follow-through of the patient after he leaves the center can be assured.



Most of the centers that now exist do have the dedicated staff--probably many of them could be greatly strengthened by some additional personnel in one area or another. All of them, I am sure, are well taken care of already in terms of outpatient facilities and the acute type care bed. I think one of the major needs is for the continuing care bed--the type of unit where the patient can be cared for after he no longer needs the intensive study. Also, most of the centers could be helped, I am sure, with the development of a program of continuing monitoring of the patients need after his discharge.

Having said that much, let me turn to my second part of my topic which is that of Maine. Let me qualify myself here by saying that for the last five years it has been my home. For some 68 years before that it was a summer home. Recently I have been closely associated with the program that you just heard discussed by Mr. Schott and Mr. Kerr it can accomplish. But our great problem in Maine is that, whereas there is good service for the rheumatologic patient available in Portland--the major city of 65,000 people, outside of Portland, when I settled there in 1970, there was no rheumatologist serving the general population. The situation isn't too much different today. I am able to, on a part-time basis, serve an area some 40 miles north of Portland. Another physician has recently settled in an area some 60 miles northwest of where I am, and it is expected that very soon a new physician, a rheumatologist will come to Bangor. But the great bulk of the population of the state, of the million that was mentioned earlier, is scattered in a tremendous area of thin population and for these people, rheumatologic services are really lacking.

To my mind, at least part of the solution would be taken care of with three measures: the first would be the designation of the Maine Medical Center in Portland as an arthritis center; secondly, a program of transportation to get the patient from the outlying areas to such a center when it is needed; thirdly, a system for the follow-through, the continuing monitoring of the patient's care after discharge.

Now, I just want to say a word about the Main Medical Center. Although there is no state university medical school in Maine, the Maine Medical Center is a--in every sense--a university-type hospital. It has an excellent staff of rheumatologists, orthopedics and other allied health personnel and a fine basic research and clinical research program in rheumatic diseases with an important teaching program for both undergraduate and graduates as well as a splendid physical plant. A moderately small amount of money to perhaps provide additional personnel where they are needed and a system that would work to bring the patient who needs this kind of care to such a center, I believe would be a most efficient way to solve a large part of the problem that today exists in Maine. Even when the happy day comes when there will really be enough rheumatologists to fill the need throughout the state, such a development would never replace the need for a center. Because of the fact that Maine is largely rural, the people are widely scattered and it is unlikely, and impractical indeed, that real rheumatologic talent is going to be nearby all of the patients who need it.

ENGLEMAN: Thank you so much, Dr. McEwen. Yes, Dr. Batchelor.



BATCHELOR: As I listened to Dr. McEwen giving his account of the special characteristics of Maine and the needs of a rural population, there came to mind the rewarding experience of the consultant group working with the Commission. I paid a visit to the Canadian Arthritis Research Unit in Vancouver, where we heard some description of a similar problem and exploration of a reverse flow, if you will, to try to develop mobile units that particularly would take qualified people working in just the area that Mr. Schott has described for us, but instead of bringing the people in because so much has to be done in the setting of the home taking them out. I wondered whether you had given this device--the mobile unit that would take people trained in occupational therapy but really home modification and physiotherapy--any thought? Is this prohibitively expensive? I have no notion of what it would mean and have only the vaguest idea of how this would compare with bringing them in.

McEWEN: It's one of the measures that I have thought of as being able to do two types of things. The first is that important question of how you make sure the patient who has been in the center and now has gone back, that one can continue to monitor that type of care. I think that in a rural area like this, and of course I am sure Maine is not very different from many other rural areas--except that we have more snow than most in the winter time, which makes transportation more difficult--this would be very helpful in monitoring the patients after continuing care, after leaving the center. The other, for the patient who is less severely ill, who doesn't perhaps need the intensive study and beginning care that he would get in an arthritis center, this need could also be met by getting a rheumatologist out to the community where he would see these patients. Let me say that, through the Arthritis Foundation, and I again want to commend what is being done there, it is possible now, in a beginning way, to get the rheumatologists who are available out into the more isolated hospitals to spend a day. And this is going to help, but it is going to be a long time before there will be enough rheumatologists in the state to meet the needs and that is why I outlined this threepronged approach as to the best way, as I see it, to meet the immediate problem.

BATCHELOR: Mr. Chairman, could I just comment that the last point which you covered about the outreach effort where trained physicians go to outlying hospitals, this is a subject of recurring interest, again particularly to our community program work group, and if you had even a brief summary account of your experience with this to date, I know that this would make a valuable addition to their compilation of experience, to date, with this sort of program.

McEWEN: We will see that you get it.

ENGLEMAN: Thank you, Dr. McEwen.

TESTIMONY OF  
WALTER CALLAGHAN  
YELLOW CAB OF BEDFORD, MASSACHUSETTS

CALLAGHAN: Thank you, Mr. Chairman and members of the Commission.

I am Walter Callaghan from Yellow Cab of Bedford, Massachusetts. I have been engaged in the transportation industry for the past 27 years as a manager and an owner in the New England area. During the past year and a half, I have had the personal opportunity to observe the transportation needs of the arthritic person because drivers are selected and assigned to the transportation of these patients. This creates a more personalized relationship between the driver and the patient. There exists a tremendous void in public transportation for the handicapped. There are approximately 3,361 communities served by taxicabs as compared with 1,079 communities served by bus and rail transit. Thus the only form of public-passenger transportation in 2,282 or 68 percent of the communities is the taxicab. This is why we feel that the taxicab industry plays an important role in the transportation of the handicapped.

Our industry has been performing this service on a personalized basis for over 50 years. The arthritically-handicapped person is, many times, unable to use the present forms of mass transportation for his personal transportation and medical treatments. In southeastern Massachusetts hospitals for the arthritic are located 50 to 60 miles away. The Umpter Act of 1970, that is the Urban Mass Transportation Act, mandates that there shall be mass transportation for the elderly and the handicapped to all urban areas; In regard to the handicapped, that they shall be able to use a dignified means of transportation. Once again I feel that the taxi industry fulfills the transportation needs of the handicapped person better than any other form of public transportation.

I urge the Arthritis Commission to explore fully the transportation needs of the arthritic and suggest that funding be sought for their transportation in the form of transportation stamps where the rider is subsidized and can choose his own form of transportation for his own needs. This concept is presently in the research and development study form, funded by UMPTA in West Virginia and, in various stages, in several other areas of the country.

In conclusion, I would like to cite a typical local example. In southeastern Massachusetts, a regional transit authority was formed under the UMPTA Act, with Federal, state and local funding. Under the UMPTA Act, authority must provide one-half fare transportation on off-peak hours to the elderly and the handicapped. Approximately one year ago, the local authority provided free bus transportation to the elderly. At that time, I met with the council on aging and asked that some consideration be given the handicapped person in the form of some amount of discounted fares to be applied against the taxicab ride for the handicapped. On October 1, 1975, the local transit authority announced that the handicapped were to ride for half fare on off-peak hours, which are 9:30 to 2:00 p.m. How are the handicapped and the arthritic person going to get on and off the bus without the personalized attention that only a taxicab driver can give? What happens before 9:00 a.m. and after 2:00 p.m. when the transportation

is needed for the arthritic? The position I take as a taxicab operator is that this is only a small portion of the total transportation picture and does not satisfy the total transportation needs of the arthritic person. I thank you.

ENGLEMAN: Thank you very much. Would the legislation that has been passed in this city or state be available to the Commission, a copy of it, with regard to transportation?

CALLAGHAN: It is all in the UMFTA Act that is the Urban Mass Transportation Act which dictates as to what is available to funding.

ENGLEMAN: Would you be good enough to make a copy of that available to this Commission?

CALLAGHAN: Yes, I would.

TESTIMONY OF  
CHARLENE MURPHY  
MOTHER OF JRA PATIENT

MURPHY: My name is Charlene Murphy. Lynne Marie Murphy is a typical nine-year-old with the usual great hopes and aspirations for her future. As her mother, I hope and pray that she will be able to fulfill her wildest dreams.

Lynne has been battling juvenile rheumatoid arthritis since she was 18 months old. This is probably the most misunderstood disease to date. Many old wives tales surrounding arthritis contribute to this factor. The need for greater awareness of this children's disease is essential, especially among physicians and school personnel.

It has been my experience while seeking medical help for my daughter that too many physicians simply are not able to recognize this disease in children, therefore, causing painful lapses of precious time before treatment. School personnel is a special subject to me because Lynne is in her prime-growth years, both academically and socially. Educators must be made aware of the special needs of children with JRA. Some of these are: transportation to and from school; physical therapists on a regular basis to enable a child to keep up his daily exercise routine; and a nurse to administer eye drops when needed, sometimes up to every two hours.

More information needs to be made available under Chapter 766, to improve benefits to JRA children. After doing extensive research into 766 be participating in many modules, task-force type committees and even being a volunteer census taker for this program, I have yet to find where juvenile rheumatoid arthritis fits in. Believe it or not, many educators think these children have anywhere from a severe learning disability to being mentally retarded. It is not easy to explain this disease and what it entails, as each child's involvement varies, but it is even harder, when a stigma has been attached to remove it from his mind without continued improvement in public awareness.



More facilities are needed to accomodate patients, to expand research, especially in areas regarding the eyes, the liver and the connection between the measles vaccine and arthritis.

Juvenile Rheumatoid Arthritis is a children's disease that has long been pushed into the background. It is time that these children be recognized and given the attention they deserve. I only mentioned a few pertinent needs in my testimony, but there are countless more. Start somewhere, please.

ENGLEMAN: Thank you, Mrs. Murphy. Would Lynne Marie like to speak now?

TESTIMONY OF  
LYNNE MARIE MURPHY  
PATIENT

MURPHY: My name is Lynne Marie Murphy. I am nine years old and I have juvenile rheumatoid arthritis. I hope when I get older my kids don't have arthritis so that they won't miss out on some of the things. If they have it bad in their legs or their arms, they may not be able to run fast or throw a snowball or to throw a ball or have snowball fights, or play in the rain.

They may have an eye disease and may not be able to see that well and can't read books good. I hope they find a cure before I grow up. I hope I never hear of it again in my whole life when I get older. If this doesn't happen, I hope we can have more places like the Robert Brigham Hospital for helping children and doctors and nurses that understand kids with arthritis and more studying to find out more to help us.

ENGLEMAN: Thank you very much, Lynne Marie. Lynne Marie, if you had your choice, what would you like first of all, first and foremost.

MURPHY: A cure.

ENGLEMAN: A cure, that's reasonable. How about you, Mrs. Murphy?

MURPHY: I would have to agree with Lynne, a cure, but as I mentioned in my testimony, Chapter 766 is a program that is Federally funded, I believe to help children with special needs and when I heard this I became interested because I felt I had a child with special needs, but there is no mention of a child with rheumatoid arthritis and I think this is mainly because of my community. I am vocal, it is aware that children do have this, but I am sure many communities are not made aware that these children do need transportation, etc.

ENGLEMAN: Thank you. Dr. Calabro.

TESTIMONY OF  
JOHN J. CALABRO, M.D.  
CHIEF OF MEDICINE AND DIRECTOR OF RHEUMATOLOGY  
WORCESTER CITY HOSPITAL  
PROFESSOR OF MEDICINE, UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL

CALABRO: Dr. Engleman, members of the Commission:

Lynne Marie and Mrs. Murphy are going to be hard acts to follow but I think they probably tell the story and the problem that I am going to direct my attention perhaps more vividly than I can in my short two or three minutes. I would like to provide data for the need of special arthritis centers for children with rheumatoid arthritis.

I am Chief of Medicine and Director of Rheumatology at Worcester City Hospital and Professor of Medicine at the University of Massachusetts Medical School, both in Worcester, Massachusetts. I am a Consultant in Pediatric Rheumatology at the New England Medical Center and Professor of Pediatrics at Tufts University School of Medicine--as an example of where the doctor travels 50 miles to go to an arthritis pediatric arthritis clinic from Worcester to Boston.

Juvenile rheumatoid arthritis affects an estimated 250,000 American children. Despite its frequency, it continues to remain the most common cause of crippling from childhood arthritis and one of the leading pediatric causes of blindness from chronic iridocyclitis or inflammation of the anterior chamber of the eye.

Crippling and blindness often result because juvenile rheumatoid arthritis is still regarded as a disorder that begins similar to rheumatoid arthritis in adults: with multiple swelling of several joints. What is not widely appreciated is that ten percent of children with rheumatoid arthritis begin with an acute febrile onset. This is characterized by high fever (as high as 106 degrees Fahrenheit) rash, enlargement of lymph glands and other extra-articular manifestations for weeks, months and even years before joint swelling occurs. These patients are labeled as having fever of unknown origin and are repeatedly hospitalized for diagnostic studies, including surgical exploration, and are given multiple courses of needless antibiotics. Nor is it widely known that about 30 percent of juvenile rheumatoid arthritis patients begin with swelling of only a single joint or a few joints--a form we call oligoarticular onset. Consequently, early diagnosis is delayed and the benefit of early effective treatment is lost to the child.

Within recent years, it has been shown that children with the mildest form of juvenile rheumatoid arthritis--the oligoarticular form--are prone to develop chronic iridocyclitis, anywhere from 20 to 40 percent. What is even more perplexing is that in the majority of children the ocular inflammation smolders quietly until failing vision alone compels attention. Blindness can be prevented in the majority of children with regular ophthalmologic exams conducted every three months. Such routine ophthalmologic screening facilitates detection of asymptomatic iridocyclitis early enough for treatment to be effective and blindness to be averted.

Actually, the frequency of loss of vision runs as high as 50 percent in centers for routine screening is not being provided to children.

Special arthritis centers can provide multidisciplinary care so that specialists can provide means for early diagnosis of rheumatoid arthritis in children, generally, and detection of potentially serious manifestations before crippling or blindness can result. These centers can also provide special care and physical therapy so as to prevent deformities or to correct those that already exist. Comprehensive centers can undertake trials of drugs, both old and new ones on the horizon, since currently there are only a limited number available to children with rheumatoid arthritis. In fact, half of the drugs available to adults, such as pherylbutozone, oxyphenbutizone, indomethacin and the newer one, ibuprofen, are contraindicated in children simply because their effectiveness and safety have never been tested in children with rheumatoid arthritis, nor have the number of potentially promising surgical procedures, such as early synovectomy and soft tissue releases for correction of contractures.

In a setting of comprehensive care such as a special treatment center, like two of the centers I have been associated with, what can we expect? In a setting of 100 children now observed prospectively for close to 17 years in New Jersey, 64 are in remission. They are not taking any drugs and have no evidence of systemic or articular disease. All 64 patients--most are now young adults, the average age is 18--are in the American Rheumatism Association functional classes I and II and are therefore capable of all ordinary activity. Of the remaining 36 patients, 3 died and 33 continued to have active rheumatoid arthritis. However, of these 36, only 13 patients are in the unfavorable classes of III and IV and thus capable of little or no activity. Seven of these were actually deformed when first referred to us.

These figures are reassuring when one compares data from older series where the death rate was close to 20 percent and only a third of the patients entered adult life free of deformity. Clearly this enhanced outlook depends on regular followup care because juvenile rheumatoid arthritis is a capricious disease that can change at any time in its long course. We need more specialized treatment centers. There are not more than a dozen or so directed to children in our country and I hope that this Commission will include this kind of facility in their recommendations to Congress. Thank you.

ENGLEMAN: Thank you, Dr. Calabro. Any questions?

I gather that you think that merely an addition or presence of a pediatrician on the staff of an arthritis center does not offer the same opportunities as a center that is exclusively pediatric in its orientation?

CALABRO: Yes, unless this pediatrician has been trained in pediatric rheumatology

ENGLEMAN: Assuming that we have a pediatrician who has background in rheumatic disease, would you still feel that there is some unique



contribution that a pure pediatric center offers that is not available elsewhere in other centers?

CALABRO: Yes, primarily because one needs many other skilled specialists to be involved in the child's care. This is to be optimal. And that means, of course, not only the pediatrician, or the pediatric rheumatologist, or the rheumatologist and the pediatrician if the pediatrician is not trained in rheumatology, the social worker, all of the other paramedical people, transportation, people, nurses that can go into the home, nurse coordinators, physiatrists, and physical therapists, orthopedic surgeons and obviously the ophthalmologist because the ocular problem is unique to children and not adults with rheumatoid arthritis and the one mild form of the disease that I mentioned where children have swelling of only one or a couple of joints. Even when that swelling is in remission, and therefore quiescent for as long as five years, the child can get iridocyclitis, and the frequency in longterm follow ups that are just coming out and being published is as high as 40 percent; that is, at least one out of three children with this form of disease. Our experience is closer to one out of every four children. Does that answer the question, Dr. Engleman?

ENGLEMAN: Not really, because in teaching centers there is always an ophthalmologist who is present. The allied health people are there, but what I want to hear from you is whether or not you feel that the allied health people, for example, need to be trained especially in pediatric rheumatology.

CALABRO: Yes, I think they do need to be trained in pediatric rheumatology, because I think the considerations of physical measures--and, indeed, even orthopedic care--require special training in either pediatric physical or pediatric orthopedic surgery. For a long time in my early days in New Jersey, we would refer most of the children who needed corrective surgery, most of the children with rheumatoid arthritis to centers either in Boston or in New York City, and funds were provided by the Crippled Children's Association of New Jersey simply because there were no doctors who felt qualified to treat these children.

ENGLEMAN: How would you feel about a supplementary aid given to crippled children's hospitals like the Shriner's Hospital, to have a specific department in rheumatology and the training for as well as the care of?

CALABRO: Some of them do. I am familiar, of course, with the one in Springfield, and there they treat a number of children with rheumatoid arthritis. I actually see perhaps 20 or 30 of them periodically for medical care, and much of the physical measures are employed there at Shriner's Hospital in Springfield. I think most of them don't have people that are trained particularly in the techniques of care for children with rheumatoid arthritis and there is a great need for those.

ENGLEMAN: Yes, Dr. Sharp.

SHARP: Assuming that the manpower is inadequate, would you say that the first step that needs to be taken is to encourage training of more people with expertise in pediatric rheumatology?

CALABRO: Yes, I think that we have to train more people, particularly in pediatric rheumatology. The problem, of course, is that we now have just a handful of centers who do this. You can get a rheumatology fellowship in many of the key centers that are affiliated with medical schools throughout the country, but when it comes to getting special training in pediatric rheumatology or, for that matter, to include this as part of general training in rheumatology, this is often lacking. I'd like to make a plea that somehow this deficit be corrected, echoing again the words of our patient and her mother.

ENGLEMAN: Thank you very much, Dr. Calabro. Dr. Kaplan?

TESTIMONY OF  
STEPHEN R. KAPLAN, M.D.  
HEAD OF THE RHEUMATOLOGY PROGRAM, BROWN UNIVERSITY  
DIRECTOR, RHEUMATOLOGY CENTER, ROGER WILLIAMS GENERAL HOSPITAL

KAPLAN: Dr. Engleman, ladies and gentlemen of the Commission:

My name is Dr. Stephen Kaplan. I am responsible for the arthritis program at the Brown University and the Rheumatology Center at the Roger Williams Hospital in Providence, Rhode Island. I would like to take this opportunity to direct to you some specific remarks relevant to what I think are but a few of the many concerns that fall within your task.

First, I would like to make you aware of some of the major gaps that exist in our Rhode Island community relative to the needs of patients with arthritis and musculoskeletal disorders and I would suggest that this is probably true in many other areas. For example, occupational therapy was just recognized for third-party reimbursement for inpatients by Rhode Island Blue Cross only as of January 1, 1975, and it is still not recognized for third-party reimbursement for the ambulatory patients who may have the greatest need for these services. In addition, there is totally inadequate reimbursement available to patients for physical therapy on an outpatient basis. We would like some formal recognition, possibly through this Commission or through an arthritis act, of at least minimal and, hopefully, optimal facilities and resources for the care of patients with arthritis and related diseases that need to be developed and made known to the appropriate health care agencies and those responsible for providing adequate forms of health insurance to our population. We urgently need the systems and resources that can provide a continuum of care for the direct benefit of the afflicted individuals. As part of this effort and to document the needs of the community, we feel that a registry program is required.

In our community, we are initiating a long-term care study employing a function data base. We expect that this program will provide a regular and informative feedback evaluation to the physician caring for each patient in the registry and suggest that any national registry should have



in it the same attributes. It is our opinion that the results we achieve with our ability to provide health care and with our advances in research must be the ultimate measuring stick of our success or failure.

Secondly, we need the impetus to draw all the interested forces together including academic centers, physicians and allied health professionals, as well as voluntary and state agencies to develop a unified plan with a variety of approaches to educate the public regarding the identification and early detection of forms of rheumatic diseases. A major need is for the education of medical personnel as well as lay personnel regarding the potential for effective treatment--that which is even currently available for many individuals with rheumatic diseases--and to dispel the philosophy that you have heard here so often this morning, that arthritis is something you just have to live with. The proper coordination of outreach can make the avenues of care known within the framework of the community where it is most successfully accomplished. This requires that regional planning by collaboration of all interested centers must be encouraged so that there will be cooperation rather than fragmentation of effort and the useful exchange of ideas in educational and other endeavors.

The third point I wish to speak to, of course, is the support of research. As a clinical pharmacologist as well as a rheumatologist, I believe I would like to make a point in support of basic and clinically-applicable research in the area of therapeutics relative to the treatment of rheumatic diseases. Not only is there a need for the rational development of new approaches, techniques, and medications but there is also a need for us to better understand the potential for drug interactions and the adverse effects of therapy. As health professionals interested in this field, it is incumbent upon us to develop and promulgate a balanced, credible understanding of the benefits that may be achieved and to dispel the distorted fears regarding our therapeutic modalities. This, of course, requires extensive education of the medical profession and the public regarding the potential for benefit for treatment both at present and in the future. And for example, many physicians and patients alike in our community, and I am sure throughout the country, are apparently unaware that our current modalities are directed against the mechanisms of disease rather than just to kill pain. I appreciate this opportunity to speak to you and hope that you will bring to bear the appropriate attention and resources to deal with this major health problem with which so many millions must deal each and every day of their lives. Thank you.

ENGLEMAN: Thank you very much, Dr. Kaplan. Dr. Batchelor.

BATCHELOR: Might I just mention to Dr. Kaplan that I appreciate his reference to an experimental effort to develop a registry, and I would ask that if he had any descriptive material that he might submit with his written testimony, we would be very happy to make use of it.

ENGLEMAN: Ms. McCann.



TESTIMONY OF  
VIRGINIA MCCANN, R.N., M.S.  
REGION I COORDINATOR, ARTHRITIS FOUNDATION  
ALLIED HEALTH PROFESSIONALS NATIONAL SECRETARY

MCCANN: My name is Virginia McCann. I am here today representing the Arthritis Foundation as Coordinator for Region I, which is the New England states, and I am also National Secretary for the allied health professions of the Arthritis Foundation. Kerrently I am also on the Board of Directors of the Massachusetts Lupus Foundation. I am a registered professional nurse.

My statement is as follows:

The figure that 20 million Americans suffer from arthritis is a well-known statistic. Other related conditions are usually not appreciated as a statistic either, until they "hit home." Systemic lupus erythematoses or scleraderma or polymyocitis can severely and abruptly alter the erethemotosis or scleraderma or polimiccidus can severly and abruptly alter the lives of too many people and their families.

It is my intent today to focus on the contribution that those of us in the almost 20 recognized allied health professions can make to improve the quality of care for these perscns. I am convinced, as is Dr. McEwen, that the team approach is essential in the development, implementation, and evaluation of dynamic treatment programs. These individualized programs are directed to the prevention of deformities, disability and helpless crippling so often associated with the diagnosis of arthritis and related conditions. The goals for these individualized and dynamic programs involve education, research and the delivery of quality patient care. The needs include:

- (1) Public education to increase awareness of these diseases and the expectations the patient should have for quality care.
- (2) Professional education which we heard spoken of before, also. I agree it should be of a basic as well as a continuing nature with experience in appropriate clinical settings with proper supervision.
- (3) Patient care centers with focus on the ambulatory as well as inpatient care.
- (4) Consultant services in the broad area of health promotion as well as health care delivery.
- (5) Inclusion of community health agents, the involvement or outreach clinic--as Dr. McEwen referred to--referred to in the vital aspect of continuing care.
- (6) The vocational implications spoken of earlier in preserving the dignity of the individual and the family.

- (7) Research in the response of patients to the accepted modalities as essentials of both the diagnostic as well as the treatment phase of the disease.
- (8) Research in the response of other measures determined to have meaning in the prevention of deformities or the promotion of health in the field of rheumatology.

I personally want to express my gratitude on behalf of my profession and the patients I represent for the Commission's interest in the improvement of care for patients and families as well as its appreciation of the contribution that those of us in the allied health professions can make in the delivery of health care.

ENGLEMAN: Thank you, Ms. McCann. Questions? Yes, doctor.

VOICE: I wonder if you would want to make any recommendations for what is most important in terms of successful outreach in the communities by centers? What is the main thing that will determine the success or failure of that effort?

McCANN: My first flush reaction to your question is education rather than training. I believe that many of us need a total education in terms of understanding the disease and also understanding what each of us as allied health professionals have to compliment the team working together with the physicians. I think we often get involved with some rivalry. We want to give the care, but we don't want to cooperate with others. So I would say it is education, collaboratively.

ENGLEMAN: Thank you, Ms. McCann.

TESTIMONY OF  
EDGAR S. CATHCART  
PROGRAM DIRECTOR, ARTHRITIS SECTION  
BOSTON UNIVERSITY MEDICAL CENTER

CATHCART: Mr. Chairman and members of the Commission:

We at the Boston University Medical Center and Boston City Hospital--primarily the concerns of Dr. Alan S. Cohen who is Chief of Medicine at that institution and and myself, Edgar S. Cathcart, Program Director of the Arthritis Section at the new medical center--fully endorse the viewpoints of others with respect to the importance of basic research and medical education in the arthritis field. We would further emphasize that arthritis has broader connotations than the public sometimes realizes. Joint disease is clearly part of the aging process and, while the child with arthritis will easily become part of a foundation poster for fund raising and certainly deserves the best of care, the major problem as we see it in our field today is really how to take care of the senior and not-so-senior citizen who is afflicted by low back pain or sciatica or bursitis or plain old fashioned osteoarthritis. Basic and applied research should devote itself to these problems, combining the best of biophysical, biochemical and immunological techniques.

This morning, however, we would like to stress an aspect of the arthritis problem that is uppermost in the minds of those of us who have responsibilities for large numbers of patients in the urban setting. By way of background, the city of Boston has one acute-care hospital, the Boston City Hospital, two chronic disease hospitals, the Mattapan and Long Island Hospitals and a network of neighborhood health centers, seven of which relate directly to the Boston City Hospital, and, finally, an evolving home care system. It is not generally appreciated that some of the satellite neighborhood centers such as East Boston and Harvard Street in Robury handle as many patients on a busy working day as most of the adjacent large urban hospitals. It is also not fully realized that while as many as 15 competently trained physicians and additional allied health personnel care for the needs of patients attending arthritis clinics, say at the Boston City Hospital or the Mass General Hospital or the Robert Breck Brigham Hospital, not even one primary care physician or nurse with special training in arthritis is available at the neighborhood health centers.

Therefore, in answer to one of the charges of the Commission and the question, do we believe that there should be centers for the care of arthritis patients, we would say yes, but perhaps our concept is this: an individual research program may or may not qualify as a center. A center should have a broader perspective, be able to ultimately meet the needs of a wide spectrum of patients and problems, and be available to persons from every segment of the community.

I will close by bringing to your attention a specific finding in our own pilot-care arthritis center which envelops the city hospital and its neighborhood health clinics. Patients who first come to the doctor with an arthritis problem deserve, and often receive, at least one hour of his valuable time. On the other hand, many more hours are needed before that patient and his family understand the problem--the need for special drugs, and precautions about the use of these drugs and the impact that this arthritis problem may have on the patient and his relatives. There is no way that we can presently cope with the total arthritis problem unless more comprehensive centers are developed where skilled medical and allied health professionals work as a team. Furthermore, we would urge that urban models such as the one we are developing test the efficiency of their health care delivery by evaluating the methods attempted and by obtaining direct feedback from the satisfied and dissatisfied consumers, namely the patients and the referring physicians. By these methods we look forward to the day when an initial outlay in manpower and expenses will eventually cut the cost and bring the arthritis problem under control. In a sense this morning I speak for a vast majority of patients who don't even know they have an arthritis problem. Thank you.

ENGLEMAN: Thank you, Dr. Cathcart Any comment?

In the evolution of your plan, do you already have some system with which you can do some prospective evaluation, I am thinking specifically of your outreach satellite clinic. I presume this must be a difficult problem if you don't even have a physician in attendance, or at least a trained physician in attendance. Do you have some plan with which you are going to evaluate your efforts?



CATHCART: We have plans, Dr. Engleman. It is exceedingly difficult to implement them. I think the first thing that really surprised us was the, to use the cliché, the magnitude of the arthritis problem in the area that we are studying. Now this basically has gotten us into again epidemiological approaches, trying to find out how many patients actually do have back pain or bursitis, etc. Then, when it comes to actually evaluating what quality of care is necessary, it becomes difficult and we are adhering to the principles outlined by the special committee from the Arthritis Foundation, namely the guidelines for medical practice. What we are attempting to do is to at least find out if every patient who comes under our umbrella eventually will succeed in getting that type of follow-up and care. As to evaluating whether patients with DJD, for example, get better if they are treated one way versus another, or in one system versus another, I think that really is a field that has to be explored.

ENGLEMAN: Thank You very much, Dr. Cathcart. May we call on Janet Aldrich.

TESTIMONY OF  
JANET ALDRICH  
BOARD MEMBER, NEW HAMPSHIRE CENTER  
ARTHRITIS FOUNDATION

ALDRICH: I am Janet Aldrich, and I have had rheumatoid arthritis for 13 years. I live in Central New Hampshire, and I am a member of the Board of Directors of the New Hampshire Chapter of the Arthritis Foundation. I have been active in fund raising for arthritis in Belknap County for the past seven years.

The key to the arthritis problem is research which needs much more support than it is presently receiving. It was over ten years ago that researchers and doctors were so hopeful for a breakthrough by the 1970's. Here it is 1975, and the cause and the cure are not known. Many drugs have been tested and are being used to help control the disease; however, arthritis is far from being conquered. In the age of rockets and putting men on the moon, it seems that science and research could come up with some answers for the arthritic. Let's get the show on the road and, with more funds, give the arthritis sufferers on earth new hope and finally some relief.

The second important area of support should be toward specially trained personnel. This means more rheumatologists and physical therapists which are needed in central New Hampshire. Laconia and Concord, New Hampshire have excellent orthopedic surgeons who perform all the new joint replacements, and we are fortunate. However, a rheumatologist is needed to oversee total treatment of the arthritic. To accomplish this at present, a patient must travel 90 miles to Boston or 65 miles to Hanover for specialized care. If the arthritic is in real need of help, he usually doesn't feel like traveling for two hours. If the patient doesn't have transportation, it presents even more problems and becomes very expensive even before he receives medical help. When a patient must travel a long distance, it is hard for the arthritic to receive continual total care at home. Either the proper equipment for

therapy is not available or personnel are not trained in the field of arthritis; therefore, it is important for more hospitals in New Hampshire to have rheumatologists on their staff.

Today, while we are waiting for a breakthrough in training our specialists, we need to support more seminars to update and train our local doctors who diagnose and treat most arthritis sufferers now. We need more arthritis clinics with trained doctors, nurses, and therapists spread through out New Hampshire. Because arthritis is a chronic, long-term illness, it is important that home-care nursing services be supported. It is important that an arthritic remain independent but still be able to have the help he or she might need.

There is great need to sponsor and support public forums to educate the general public on America's number one crippling disease. These forums need trained doctors to explain the disease and to warn against quick cures and quacks. In summary, we need a gigantic boost in research while we train more doctors and support programs on local levels so we may reach all arthritis sufferers, not just the ones who can afford special help. Thank you.

ENGLEMAN: Thank you, Miss Aldrich. Dr. Burnett.

TESTIMONY OF  
JOSHUA B. BURNETT, M.D.  
STAFF RHEUMATOLOGIST  
DARTMOUTH HITCHCOCK MEDICAL CENTER

BURNETT: I am Dr. Joshua Burnett. I am a staff rheumatologist at the Dartmouth Hitchcock Medical Center, and I am speaking also for Dr. Edward Harris who couldn't be here today. He is the Director of our Connective Tissue Disease Center at the Dartmouth Medical School. We are very glad Mrs. Aldrich could come today and say what she said because she truly states the needs in New Hampshire which are not too much different from what others have said here.

Let me just say a couple of specific things. But first, about our own center, we certainly support the concept of centers for the diagnosis and treatment of arthritis. At our center, the medical school is the crux of it, and like most medical schools ours has budgetary problems. We have a small but active group but the medical school doesn't see where in their budget they can support another full-time rheumatologist in the near future, and we certainly need one. For instance, we don't have a strong immunology department. We don't have enough in the medical school budget to have one soon.

Another aspect of the center is a continuing care facility. This can be part of the present hospital, but we would strongly urge the support for special physical therapists, special personnel to collect the data for one thing and join the data bank, to instruct patients in home care, and so forth and to provide cheaper hospitalization care while they are recovering from a chronic disease. This can be done with our facility but the staffing is important and so is special instruction. I would like to



speak of the problem that Mrs. Aldrich mentioned. For a long, long time, I was the only rheumatologist in New Hampshire, and now Dr. Harris is there. There are two or three other doctors who have a special interest in arthritis but practice general medicine. Certainly I have to rely on a local private physician for a long time and we feel committed to the fact that they come to our center from 100 miles away, stay for two or three weeks, or maybe a much shorter time for diagnostic treatment, but then our effort is to get to the physician's home, talk to him and give him what he has to know, go to his hospital and have consultation clinic and to reach out and help in his education because I just can't foresee that there are going to be enough rheumatologists for a long time to take care of all the people in all the different corners of New Hampshire.

Finally, about allied health care, we have leaned heavily on the public health nurses, the state public health society and then the local district nurses, who are the most enthusiastic people in the world in responding to any education effort that we have put out, and we have tried little efforts, but this could really be enormously boosted and these existing facilities be greatly strengthened. And then I think that the biggest problem with arthritis, as others have said, is that so much of it is done and cared for in the home and that the home physician, the home public health nurses, the home physical therapist and our continued intermittent presence in the community whenever we can and then having the patients coming come back to KV, these efforts in education need a lot of support and a vast amount of increase--they just don't deliver them enough at present. I think that in the studies of the family, social workers and psychologists can help us, and we need to go to the patient's hometown and his home physician to boost his care and this is expensive training.

ENGLEMAN: Thank you, Dr. Burnett. Any comments, Dr. Batchelor.

BATCHELOR: Dr. Burnett, you mentioned your interest in helping the primary care physician; I might just mention that the group of consultants working with the Commission on the education problems, covering the span from patient education to the specialists, have been giving particular attention to this area and, if indeed you have any experience in reaching the physician, bringing them into your center, etc. we would appreciate it if you could add to your material that you submit along with your presentation today, any reports that you have in this area. It is very difficult to get firsthand information on what people are actually trying today, where you see the pitfalls or where you see the opportunity for development along these lines.

BURNETT: Well, we have a couple of seminars on arthritis with invited speakers. We have had them on one afternoon, Wednesday afternoon, many people's afternoon off and the time of good weather in New Hampshire and 50 physicians came to these, which is really pretty good and that was one way.

BATCHELOR: Can you get any idea as to response to this, apart from attendance, can you see anything of impact?

BURNETT: Well, that is very hard to measure and I can't really measure it, but they seemed enthusiastic at the time. We wrote to every



hospital in New Hampshire and offered our services to come as consultants, Dr. Harris and myself, and many responded. Two thirds of them responded. And we tried during the course of a couple of years to go to those hospitals and the response there varies enormously--sometimes you will get a local man who is really interested and will whip up a good group and bring their patients in and we will treat three or four of them. This seems to us the best way to do it. Because there isn't a rheumatologist in Concord, New Hampshire, the orthopedists there have asked us to come down, and we go every other month and just meet with them. There their internists haven't come but their two orthopedists there are really interested and have helped a lot in their responses. It is great and they are looking for a rheumatologist. But I think the local physicians do want to do the job and will respond to reaching out. This takes time and effort and money.

ENGLEMAN: Thank you very much. We will call on Mrs. Cook.

TESTIMONY OF  
MRS. HELEN COCK  
MOTHER OF SLE PATIENT

COOK: Mr. Chairman and members of the Commission:

I would like to testify as a frustrated parent of a 20-year old daughter who, after three years of going through examinations with dermatologists, internists and various other doctors, was finally diagnosed as having systemic lupus erythematosus, a disease, of course, none of us had ever heard of. During these three years, my daughter would often have a butterfly rash across the bridge of her nose and her cheeks. Also, on occasion, she would complain of her knees being sore and other joints, but because she was an athlete and an avid skier, we didn't pay too much attention to this. She was also very irritable, and I thought perhaps it was just teenage years, but quite frankly, now I don't think she ever knew what it was to have a good day. After high school graduation she completed a perfect college check up and was getting ready to leave one week later to be a counselor at camp in Maine which she dearly loved. Two days later she approached me after sunning herself and said, "Look Ma, I can't bend my fingers." So, with that, I said, "You are not going to Maine feeling as lousy as you do. I am going to call a new orthopedic man who has just come into the city." And I did. He saw her immediately and when he took one look at her face and her fingers, he had a visiting young internist, a physician in that office, and at that time I clearly remember his saying lupus. Well, I didn't know what lupus was, and he looked at my daughter and he said, "I want three days of intensive blood testing to be done next week." Well, I said, "She is leaving for camp Friday." He said, "Well, we will start today." So she had the blood test and, on the night before she was to leave, we received a call from the orthopedic doctor's office and he said that he had already spoken to our internist and to call him immediately that she had a disease called lupus and he would explain it to us. Well, I called him and he said please come down with your husband and your daughter. I would like to see you all immediately. From that time on it was a complete nightmare. Needless to say, we were very frustrated and heartsick. Perhaps, if three

years ago one of these many doctors had recognized the disease, our daughter may not have been so ill. She does have kidney involvement, but thanks to the Robert Breck Brigham and Dr. Peter Shore, she is getting better. She happens just by coincidence to be a junior at Boston Sargent School of Allied Health. She is going into speech and hearing therapy.

I feel that there is a definite and immediate need for further education in patient care for doctors and nurses in this disease and, of course, for research in systemic lupus erythematosus. Thank you.

ENGLEMAN: Thank you, Mrs. Cook. Any question from members of the panel?

BACHELOR: I think it is very important for us as commission members to let Mrs. Cook know that it has been brought repeatedly to our attention that the path to competent help is an irregular one, and it is very clearly fixed in our minds that you want us to take steps to be sure that the information we have today is most widely circulated.

TESTIMONY OF  
CHARLES CHRISTIAN, M.D.  
PHYSICIAN IN CHIEF  
HOSPITAL FOR SPECIAL SURGERY, NEW YORK CITY

CHRISTIAN: The central issue in the inquiry is the patient with arthritis, and there are two striking deficiencies in meeting his needs. We have heard already about one; it is the insufficient number of physicians and allied health personnel who are really skilled and experienced in the management of chronic arthritis. The other: With the best of circumstances where a health system gives the patient access to skilled specialists, the physician is handicapped by deficiencies in our knowledge of the cause and pathogenesis of diseases like rheumatoid arthritis and systemic LE.

In contrast to some pronouncements, we are not at the position we were in the 1950's with respect to poliomyelitis where a systematic application of available knowledge will see the control of arthritis. We desperately need new information and new insight so that, when we see the patient with early disease, we can influence the course of the illness more decisively and more predictably.

What I just said has been heard, I suspect, many times by members of the Commission, and I suspect that they agree with what has been said. But I would like to speak briefly about priorities and how increased levels of support might be invested were they made available. Support could be directed into separate channels; for example, training of rheumatologists, orthopedic surgeons, allied health personnel to the training of basic scientists, to the support of patient care, to public education, to the support of research, each viewed as a separate package. Alternatively, support could be directed into programs that have as their mission all of these objectives. Whether you call such programs centers, program projects or something else is not important. But I firmly believe that this is the more promising scheme for development.



There is some uncertainty and reluctance in accepting the center concept. In part this relates to what is unknown about their size. If most of the increased support were directed into only a few programs that were called centers, I would be in opposition to that, even though I sit in an institution that might qualify for that type of support. I think we would have to accept that centers can be varied in size and varied in certain qualities. The Commission has heard, or will hear in testimony favoring the support of the separate packages, that basic science can be as productive in the relative vacuum as it can be in the collaborative venture with clinicians and clinical scientists. I know that argument, but my experience doesn't confirm it. I believe there is a very important symbiosis between those that provide patient care and others in clinical and basic research. The experience of clinicians including their frustration needs to be transmitted to the scientist, and the best of medical care does exist where there is a spirit of scientific inquiry.

So far my testimony has been diffuse. I say we need several things which in my judgment could best be realized by the support of broad, multidisciplinary programs. If I were asked to narrow the priorities among these several things, I would identify training support as the most critical need. The approaching extinction of Federal funds for research and clinical fellowships constitutes a crisis of immense proportions. I think it is an impending disaster. It is signaled to many young physicians that there is no future in clinical research. Without a correction very soon of Federal policy regarding training, we will be sealing off the talent that is needed for real progress. I think that, if I haven't been convincing on my feeling of the importance of the mission of training, I will happily go to Denver and testify again. Thank you.

ENGLEMAN: Thank you, Dr. Christian. Any comment from members of the Commission? Yes, Marlin.

SHIELDS: Just one comment. I couldn't help but recall what was said by the first patient--she referred to the fact that the country could send a man to the moon and yet we can't seem to solve such problems in dealing with arthritis. I believe that we could solve a lot of our problems if we could take the amount of money that went into that project of sending that man to the moon and put it into the arthritis programs. I am concerned that I don't recall going to a public hearing where I was asked whether I wanted to send a man to the moon, but some how that priority was set. We do have to get that kind of a singleness of focus, on a national level, so that they can see arthritis as important as, or as singularly, as they did to put that kind of money into putting man on the moon. It would solve many of our problems.

JENERICK: Did I interpret your testimony correctly, Dr. Christian, that you would feel comfortable in leaving a lot of autonomy and flexibility at a so-called center to make judgements about the distribution between research, training, service and so forth, the other activities, as contrasted to the present program where every individual research training or service requires a separate application and another year and a separate review panel and separate appropriation on it?



CHRISTIAN: I think it is inevitable that there will be some type of review apparatus to determine scientific and clinical merit of applicants for this kind of support, but I would hope that the guidelines that are formulated at sometime between now and whenever that date might be, would be sufficiently broad or flexible to not stamp the same quality and character on each program. I think there are places, institutions and people that have some unique strengths, and any new type of support such as this should allow for those strengths to be expressed in individual ways.

JENERICK: I think we have all had experience where the feds have tried to push things into a form and nothing really fits and things get lopped off or jammed in and don't seem to make much sense.

ENGLEMAN: Thank you, Dr. Christian, Dr. Burnett, and all others.

TESTIMONY OF  
RAYMOND PARTRIDGE, M.D.  
DIRECTOR, CLINICAL RHEUMATOLOGY PROGRAM, NEW ENGLAND MEDICAL CENTER  
PROFESSOR OF MEDICINE, TUFTS UNIVERSITY

PARTRIDGE: I am Raymond Partridge. I am the Director of the Clinical Rheumatology Program at the New England Medical Center and an Associate Professor of Medicine at Tufts University. I am representing the arthritis and the orthopedic units of the Tufts New England Medical Center which has cooperative links with a number of New England hospitals through its continuing medical education program.

Through the agency of the Tri-State Regional Medical Program, we have been able to develop arthritis clinics in Massachusetts and Maine and thus obtain a clearer perspective for the arthritis care needs of populations outside the large urban centers such as Boston. I use this as an outreach program.

Even in this city, the unmet needs of patients can be illustrated by the experience of a recent arthritis clinic opened in Everett through the agency of this program two weeks ago, which within a week of its initiation, is now booked up with new patients until January 1976. A large number of these patients are unable or unwilling to travel for their care or cannot afford the cost in a large medical center or private office. The same is even more true of patients living in the more distant rural parts of the New England states. In these areas arthritis care on a long-term basis is, at the best, fragmentary.

The size of the problem is large and I am sure other people will talk about this. As a measure of the effects of arthritis and rheumatic diseases, it is estimated that about ten percent of unemployment due to sickness is attributable to the rheumatic diseases, of which nearly half is because of osteoarthritis, rheumatoid arthritis, and the other arthritides, and at least a quarter are from complaints of the back, principally disc disease. There are very few measures available to assess the problem in terms of housewives or the elderly, but it must be as great or greater.

A plan to control and manage arthritis can be put forward based upon the concept of an arthritis team and on the concept of decentralization of services to provide diagnosis, evaluation of major problems, therapeutic advice for patients and medical practitioners and continued follow-up for those patients with chronic problems.

The principal advisors of the team would be a rheumatologist and an orthopedic surgeon, because in many cases the combined evaluation of advice is necessary based on the large medical center where the full diagnostic facilities would be available. The team in the local region, hospital based, would consist of nurse specialists in arthritis, physical therapists, occupational therapists and a social worker, all with special training in arthritis evaluation and needs. This group could coordinate the arthritis activities in a district, assist the patient's primary physician in the delivery of optimum arthritis care, educate patients in self-care programs, detect early changes in the disease and detect the development of potentially correctable deformities. It should be emphasized that arthritis training programs will have to be developed further as additional members of allied health professions will be needed in some areas.

One should also consider plans for the more rational placement into more suitable occupations of those patients partially disabled by arthritis, and this should proceed in conjunction with the team projects outlined. There is also a need in some areas for sheltered workshop development for those patients unable to compete in open industry. Such plans based upon a major arthritis center, decentralized in part to develop arthritis care principally in the local regions need not be overwhelmingly expensive. But I think it has to be recognized that certain aspects will also need subsidizing to some extent.

Because of the limited function abilities of many patients with arthritis, a similar limitation is placed upon their ability to earn and, in many cases, their ability to qualify for private insurance plans. In providing for comprehensive arthritis care, it must not be forgotten that the finest program that can be devised will avail naught if those patients with limited means cannot use it because of the cost.

BATCHELOR: I would like to pick up the early reference in your presentation to the program initiated under the regional medical programs. We on the Commission have considerable interest in this effort as something for which we can learn in our planning, and of course, we also have a particular interest in learning how you plan to continue what has been started there in the light of the prospect that funding for this will not continue, at least under the old form.

PARTRIDGE: Well, this is something that is exercising our minds at the present time, as to how to continue. We currently have six of these clinics going, and we plan to initiate two or three more in the next two or three months. But, as you know, the funding finishes in the middle of 1976 and so between now and then we have to try to look for alternate sources of funding. There is no doubt that in some places a clinic like this could be self-sustaining, although my last remarks about cost are very important, because one sees a fairly large number of people who are



either not qualified, they don't qualify for medicaid or medicare, and on the other hand private insurance programs don't necessarily pay for the ambulatory care that in most cases is needed. So I can visualize that we will have to seek additional funds to try to do this.

ENGLEMAN: I may have missed it in your testimony, but do you have an ongoing evaluation mechanism?

PARTRIDGE: Yes, we currently use the data base that has been developed through the Arthritis Foundation. We have been using these exclusively in these clinics-Firstly, as a matter of testing and, secondly, to try to evaluate. We also have a social worker who is attempting to evaluate the difference between what can be obtained and what is advised.

ENGLEMAN: May we now call on Miss Worcester.

TESTIMONY OF  
CORINNE BORMAN  
LEGISLATIVE CHAIRMAN  
MASSACHUSETTS DIETETIC ASSOCIATION

BORMAN: Dr. Engleman and other members of the Commission:

I would like to make a correction. I am testifying on behalf of Elizabeth Worcester. My name is Corinne Borman, a registered dietitian and Legislative Chairman of the Massachusetts Dietetic Association.

This state association is comprised of about 1,000 members who have as their objective the improvement of nutrition of human beings, the advancement of the science of dietetics and nutrition and the improvement of education in these and allied areas. The Massachusetts Dietetic Association is pleased to have this opportunity to present recommendations to the National Commission on Arthritis and Related Musculoskeletal Diseases for a national arthritis plan.

Sound nutritional status is one essential cornerstone to well-being. There is evidence that poor individual nutritional practices may not only diminish a general sense of well being for rheumatic patients but may, in fact, exacerbate symptoms as in the cases of inadequate protein intake, in relation to muscle wasting and obesity. Rheumatologists recognize that there is no single specific medically recommended dietary regime for bone and joint diseases; however, the vulnerability of this population to food faddism can lead to diminished nutritional status. This is borne out by the enormous amount of money spent each year for such concoctions as filtered seawater, alfalfa tablets, etc.

Our recommendations to the National Commission on Arthritis and Related Musculoskeletal Diseases are basic and clinical research to:

- (1) Promote the study of the effect of nutrients, trace elements and metabolites on the physiology and pathology of bones and joints;



- (2) Investigate the relationship between drugs and different methods of food processing in relation to their physiological effects.
  - (3) Increase investigations into the interaction of current and ongoing drug therapy with foods and nutritional status; and
  - (4) Support the recommendation that a qualified dietician actively participate as a member of the Human Studies Committee as well as the investigating team.
- (1) Define the community level as acute care hospital and the chronic care, primary care centers, extended care facilities and so forth;
  - (2) Review and adjust regulations and funding acts to assure availability of patient nutrition care and services by qualified dietitians on the community level;
  - (3) Develop ecology statements supporting patient nutrition care and services as a reimbursable component of the health care team and home care programs;
  - (4) Support the maximum utilization of manpower by establishing a criteria for referral to assist allied health professionals in recognizing the point at which direct intervention by the dietician is required in the community setting;
  - (5) Act as a stimulator-coordinator for periodic regional workshops conducted by existing regional and state agencies or health maintenance organizations to new information and review components of comprehensive health care delivery specific to arthritis and musculoskeletal diseases; and
  - (6) Include the practice of providing nutritional services consistent with long term care, such as meals on wheels, for those severely handicapped.

Our recommendations in the area of professional and public education: Professional education--establish and fund a committee of multidisciplinary health educators and representatives of professional organizations. Direct this committee to survey and assess current course content of academic and continuing education programs relating to arthritis and related musculoskeletal diseases. The report and their findings should include recommendations for new methods and approaches to teaching and on the public education level.

- (1) Promote funding to develop new methods and procedures for educating the patient and family in sound nutrition practices, and the detrimental effect of food faddism.
- (2) Develop guidelines and policies to assure that nutritional education will be made available to all segments of the target population with consideration of the various socioeconomic levels, educational status and cultural needs.

In conclusion, the Massachusetts Dietetic Association, in conjunction with the American Dietetic Association would be pleased to provide this Commission with any additional details or information it may require in formulating a national arthritis plan.

ENGLEMAN: Thank you. What is the official attitude of the Dietetic Association, either of Massachusetts or nationwide, toward the health food popularity? Do you have any official position?

BORMAN: Well, I think it is a concern because of the amount of money spent in this area, and I think that the promoters of health food tend to be able to make very outrageous claims and we are not able to, unfortunately. So it is an ongoing educational problem and we try our best to counsel patients and reach the public about sound nutrition concerns.

ENGLEMAN: You have educational programs that are ongoing?

BORMAN: Yes, we do.

ENGLEMAN: Thank you very much. Dr. Malawista.

TESTIMONY OF  
STEPHEN E. MALAWISTA, M.D.  
CHIEF OF RHEUMATOLOGY  
YALE UNIVERSITY SCHOOL OF MEDICINE

MALAWISTA: Mr. Chairman, members of the Commission and guests:

I am Stephen Malawista. I am the Chief of Rheumatology at Yale University School Medicine and a professor of medicine at Yale.

In the brief time allotted, my testimony will center upon the area that seems to me to deserve the highest priority for support under the National Arthritis Act, both because of its proven worth and because of its high return in productivity for every dollar spent. I refer to enrichment grants under the National Arthritis Act in support of the forty-odd arthritis clinical research centers already established throughout the country under the auspices of the arthritis foundation. Since the first grants were awarded in 1965, the foundation has supported close to fifty centers, many for several years.

These centers are devoted to patient care, to research and, as a group, they have been extremely successful in all three areas. In patient care, they have provided the most expert, up-to-date treatment possible for men, women and children suffering from arthritis. In research they have been at the forefront of investigations into the many facets of arthritis, its causes, its progression and the ways and means for improving therapy. In training, they have been primarily installations for teaching physicians, medical students and allied health professionals about the rheumatic diseases and how best to treat patients with arthritis. Although these are centers of documented excellence, their specific support was limited by necessity, last year, for example, to

\$12,000 each, or a total outlay of half a million dollars for the 42 active centers last year. How can a center see thousands of patients in a year, do first class research and carry out an arthritis training program all for \$12,000? They can't, and that token amount represented only a small fraction of the budgets of most centers. The remainder came from associations with medical schools and teaching hospitals and from private foundations, but especially from grants from the Federal government. Federal grants, the main source of support, are disappearing. Federal training grants are being phased out and Federal research grants are becoming increasingly difficult to come by.

As a result, the centers which are the backbone of our nationwide fight against arthritis are in trouble. They could make good use of ten to 20 times the figures I have mentioned or five to ten million dollars a year. New centers could be funded along the established, competitive lines. That would still leave a good deal of the appropriated money for other projects.

Some have suggested that most of the appropriation under the National Arthritis Act be earmarked for a few very large arthritis centers. I do not agree. Such institutions would have all of the disadvantages of bigness, by which I mean the huge expenditure involved in getting them going and in maintaining them, the lack of access to most patients in this country, and the fat and inefficiency that are engendered by inordinate size.

The currently established centers have none of these problems. There are at present 44 of them in 27 states. They serve hundreds of thousands of patients across our land. They compete for funding by periodic documentation of their excellence in patient care, in research and in training. They need the support and they earn it. In my opinion, they will provide the highest return on the dollar in all areas of any of the programs being considered. Thank you.

ENGLEMAN: Thank you, Dr. Malawista. I gather you would like to see most of the funds that are available, go to support the already existing so-called centers that are sponsored by the Arthritis Foundation.

MALAWISTA: That does not preclude the formation of new ones in places where they are needed and don't exist. But, yes.

JENERICK: I don't understand the terminology enrichment grant. Could you give me an idea of some of the activities funded under such a type of program?

MALAWISTA: That would take a long time. I had four minutes to speak in. But there are extensive programs in patient care and research and in training and in all of these things. They are competed for periodically. They are scrutinized very carefully, and what I am saying, basically, is that there is a great deal of talk about the usefulness of centers and I want to point out that we already have very active centers of documented excellence. In other words, the basic work has been done and I think it would be a mistake to duplicate them by establishing something separate for the sake of separateness.



JENERICK: I wasn't disputing that; I was seeking to be informed about the term enrichment grant, and I think it fits in with your testimony.

MALAWISTA: Oh, enrichment grants means giving more money to the centers that exist.

JENERICK: Right, well certainly \$12,000 doesn't go very far, as you point out.

MALAWISTA: Yes, and I also point out that that \$12,000 is a fraction of what they actually use, but most of what they need has come from the Federal government but no longer does, and that, although they are fine places and that is provable, they are starving, just that.

Now, as for the mechanisms of how to do that, I will leave that up to the experts in the matter.

JENERICK: If you had one place to use such an enrichment grant would you use it in research, or treatment or outreach services or allied health training or where -- if I can put you on the spot?

MALAWISTA: Well, I have chosen to talk about the centers so that I won't be put on that spot, because they are involved in all those things and a point worth making is that those activities complement each other. I wouldn't like to say that one of them should be stressed at the exclusion of the others because I think together they make for the strongest thrust in all those areas.

JENERICK: I think Dr. Christian made the point that the center or group was the best judge itself of where to put the emphasis and I believe, is that a fair interpretation of what you are saying?

MALAWISTA: Under scrutiny.

JENERICK: Yes, of course, granted.

MALAWISTA: Yes.

ANTHROP: Dr. Malawista, you mean to tell me that you do not want to put any of this money into the medical school centers and into other hospitals?

ENGLEMAN: The question is whether or not you think that funding should also be made available to institutions and medical schools that do not have, at the moment, arthritis foundation support. Is that correct?

ANTHROP: That's right.

MALAWISTA: No, I am not against that at all. I think funding should be made available to all institutions that are capable of operating centers and that others that are almost capable should be encouraged to do so by being invested in in this way.

ENGLEMAN: Thank you very much Dr. Malawista. Dr. Rothfield, welcome.

TESTIMONY OF  
NAOMI ROTHFIELD, M.D.  
PROFESSOR OF MEDICINE; DIRECTOR  
DIVISION OF RHEUMATIC DISEASES  
UNIVERSITY OF CONNECTICUT SCHOOL OF MEDICINE

ROTHFIELD: Dr. Engleman and members of the Commission:

My name is Naomi Rothfield, a professor of medicine and Director of the Division of Rheumatic Diseases at the University of Connecticut School of Medicine. I would like to talk to you as a representative of a new medical school, because I think that, as you well know, there have been a number of new medical schools established -- some with rheumatology programs but many without. I would like to tell you about some of the problems and some of the interesting events that occur when one sets up a brand new division of rheumatology at a brand new medical school.

The University of Connecticut School of Medicine started in 1968, and I was there at the beginning. We have been very happy and successful in that our medical students do get rheumatology teaching actually from the first year on. As we grew, we developed more programs for house staff and were able to attract other members of the division. About five years ago we were very happy to receive a center grant from the Arthritis Foundation. It has been clearly established at the University of Connecticut that there is an enormous unmet need for centers of patient care in the northern half of the state of Connecticut. We are receiving referrals from family physicians, from general practitioners, from pediatricians, and from internists from the entire northern end of the state and from the lower half of Massachusetts which is just north of the greater Hartford area. So the impact has demonstrated that a need existed in the area. The area is very sparsely inhabited by rheumatologists who are trained in this area. There are only five practicing rheumatologists between Steve Malawista's center in Yale and Vermont, New Hampshire and Boston, Worcester and Albany, so that there is a large population without rheumatologists, and we are overwhelmed with patients. We would like to be able to provide the kind of care that Dr. McEwen described which was originally provided for by the center grants when they were in full phase and when there were very few centers. That is when they received significant amount of money from the Arthritis Foundation and, as you have heard from Dr. Malawista, the center funds have dwindled and are now at the level of \$20 or \$12,000 a year. However, this has been the glue that has enabled our new center to exist, and without it I don't think we ever would have been able to start in the fields of patient care, research and training. I will abbreviate the remarks and not discuss the problems with funding research which I think Dr. Malawista has very adequately covered and would like to talk a bit about the training programs.

We have been in an unfortunate position because we were a new center, so that we had no existing training program and when we applied for, or called up the NIH to ask about submitting training grants, we were told, "Don't bother." When the grants were phased in again, we were not notified. So here we are now, five years later, with a very good program in patient care, teaching and research without a training grant at all.



So I feel very strongly that the Arthritis Commission should give very strong consideration to this.

During the last four years, I have also had an interesting experience in being on the subcommittee of the Arthritis Foundation that reviews scholarship applications and have watched as the number of applications from M.D.'s has dwindled and a corresponding increase in the Ph.D. applications has occurred, which is fine. But what has disturbed me and other members of the subcommittee is the dwindling number of physicians who are going into academic careers in rheumatology. I was horrified last week when I received the applications for senior investigator awards, which are faculty awards of senior investigators in the field of arthritis and found that of fifteen applications, ten were from Ph.D.'s. So I would like to emphasize what Dr. Christian stated when he said that we are seeing a falling off of young men and women who are committed to going into a career, an academic career in rheumatology, and I think this has primarily been due to the drying up of the training grant money and of the research money. Now at the same time that all of this has gone on, we have seen in the country a tremendous drive to establish departments of family practice, and we have one at our school. Here we have a tremendous amount of money and funds from the Federal government going into training the general physician, family doctors and, at the same time, no money to fund the academic rheumatologist who I feel are absolutely essential to train these family doctors in the field of rheumatology. The family practitioner is the man or woman who is going to see the osteoarthritic in his office and is going to see the rheumatoid, because this is ambulatory care. Yet there are no rheumatologists available with the present funding to provide adequate training for these physicians, so I would like to recommend to the Commission that some funds in the Arthritis Act should be aimed at providing additional rheumatology faculty for the medical schools that do have departments of family medicine. Thank you very much.

ENGLEMAN: Thank you, Dr. Rothfield.

BATCHELOR: I for one appreciate very much Dr. Rothfield's speaking on a range of topics that interest me very much, particularly the problems of training. Your observations on the applicant pool in the group that you have seen, I just want to mention briefly the close parallel in the pool that I have had occasion to observe, the applications for individual fellowships to the National Institute of Arthritis, Metabolism and Digestive Diseases and I would mention here, put beside yours, that in my responsibility to prepare estimates for what we will likely see in the last year, given the range that our institute covers -- arthritis, dermatology, etc. down the list, digestive diseases, hematology and kidney disease -- arthritis stood out as the one area where my estimates, based merely on continuation of what we might have seen in previous years, fell way below my estimate. My estimate was too high, the number of applicants we actually saw were startlingly low.

ROTHFIELD: Dr. Batchelor, I am on the General Medicine-A Study Section, and so I know that this has also horrified me, and that study section looks at the digestive disease grants and dermatology, and what has also startled me is the fact that there apparently is money to train investigators, it seems to be between a fellowship and a career



development award in digestive diseases. When I asked somebody why we don't see this in arthritis, I was told there are no designated funds for the person who is between a fellowship and a career development award and this might be something that the Commission might look into recommending. Because it is there for the digestive, the GI people seem to have it and the arthritis don't and I think that the reason that we are not seeing the applicants is that the young residents, when they go through their residency and they are exposed to the academic rheumatologists and when they begin thinking about going into the laboratory may be exposed to us the faculty who are under this tremendous strain of not being able to get research grants, having to sweat out the training grants, we are the ones that are telling these applicants, we may not have funds for you to do your research fellowship. And I think that it has been partly our fault, but then we have to reflect what the reality in life is from the Federal government.

JENERICK: I have a question that is intended at least to clear up my understanding of what you are saying, that you are speaking of the developing shortages in academic rheumatologists, but since there are other tracks for rheumatologists, namely private practice, do you have any information on a developing lack there?

ROTHFIELD: What we are seeing, I think, all over the country is that the funds that are available from hospitals or from the medical school for fellows are being taken by people who want to go into practice, which is very good, and I think we are training excellent clinical rheumatologists. Those people have absolutely no problem going into practice. They are barraged by letters and notices in the New Orleans meeting of the ARA so that there is a tremendous need for the practicing rheumatologist, too.

JENERICK: Well, then your point is to me even more important. What you are talking about, in effect, is the drying up of the seed corn; that is, academic rheumatologists, as they become shorter, provide less opportunities to provide rheumatologists for services in private practice.

ROTHFIELD: I think that if we keep going at the rate that we are going, we are not going to have any. There will be nobody to train anybody.

JENERICK: I understand, thank you.

ENGLEMAN: May we now call on Mr. Bump.

TESTIMONY OF  
BOARDMAN BUMP  
LAWYER AND PATIENT

BUMP: My name is Boardman Bump. I live in Vermont; I work in Massachusetts. I incurred my rheumatoid arthritis fifteen years ago when I was 51, in the area of Boston where I was acquainted with a good family doctor and a marvelous friend and counselor, Dr. Bayles, who, as you know, is with the Robert B. Brigham Hospital. So I found myself in good hands very early on which is very fortunate, because my disease progressed quite a bit before the solution to my problem was found -- mainly gold salts treatment, then not universally accepted as beneficial. Still it enabled me to progress from one who was fast becoming a cripple and carrying on with difficulty in my office and other work to one who has conducted a successful physical life these last few years. I am a success story, and I am proud of it. I think that I can attribute it to the fact that I was placed in good hands, knowledgeable people with a great hospital, Robert Brigham, early on.

I would like to suggest that if I could share this good experience with somebody else by just encouraging the expansion of the research centers for a larger geographic area and to make available to more people an enlarged number of suitably trained medical practitioners who understand this disease, I would consider my own good fortune to have been passed on to worthy beneficiaries.

ENGLEMAN: We will now hear from Dr. Harris.

TESTIMONY OF  
WILLIAM H. HARRIS, M.D.  
ORTHOPEDIC SURGEON  
MASSACHUSETTS GENERAL HOSPITAL

HARRIS: Mr. Chairman, members of the Commission and guests:

I am Dr. William Harris. I am an orthopedic surgeon who practices at the Massachusetts General Hospital. I am Chairman of the Hip and Implement Unit in the Department of Orthopedic Surgery there.

I would like to advance for your consideration three general issues. First, a major impact of any legislation proposed must be directed at the noninflammatory forms of crippling disease, osteoarthritis, as well as the inflammatory diseases so extensively discussed already today. Secondly, I wish to bring the attention of the Commission revealing new data indicating strongly the dominant role of developmental abnormalities in osteoarthritis of the hip. Thirdly, I would stress the importance of bioengineering.

First, osteoarthritis. The obvious correlation of the frequency of osteoarthritis with increasing age means that an ever-growing impact of this disease will be laid at our health resources. If you consider first the hip joint, the data from Sweden show that one out of every 100 persons over the age of 60 have disabling osteoarthritis of the hip. Beyond the

age of 85 that figure is one in 20 persons. One-third of these people are unable to carry out their ordinary activities of daily living without assistance. If similar rates exist within the United States, this leads to an estimate of 175,000 Americans over the age of 65 who are unable to take care of their ordinary activities because of the degenerative arthritis of this one joint. The increasing number of total hip replacements on an annual basis seems to substantiate this type of estimate, and ostioarthritis of the lumbar spine and knee are even more common. Osteoarthritis causes more absenteeism in industry and in the armed forces than any other form of joint disease.

Secondly, it has been long recognized that severe forms of slipped capital femoral epiphysis, congenital dysplasia, and Legg-Perthes disease lead to osteoarthritis of the hip in the adult. However, the role of the more subtle manifestations of these conditions has not been exhaustively studied. We have pooled our resources with those of the Dupont Institute in Wilmington to look at this problem.

In essence, we have found that 80 percent of all cases of what we used to call idiopathic osteoarthritis of the hip are in fact secondary to unrecognized childhood deformities. The work of Murray in England and the work of Solomon in South Africa have presented identical findings. The majority of adult osteoarthritis of the hip is mechanical in origin and secondary to developmental abnormalities. This suggests a three pronged approach: longitudinal studies of the natural history of joint development and deterioration; biomechanical studies of joint congruence pressure distribution, lubrication, etc.; and an aggressive attack on the detection and prevention and treatment of abnormal development of joints.

In relation to the question of establishment of an institute, this picture of osteoarthritis argues strongly that these concepts are better advanced in a general university hospital setting because this attack needs the patient population and medical resources with pediatric, genetic, orthopedic and biomechanical capabilities in contrast with perhaps a more narrowly defined institute.

Finally, the major importance of bioengineering. I have already alluded to bioengineering investigation of the physiology and pathophysiology of joint function and degeneration. The second major role of bioengineering is in the therapy of arthritis. The greatest advance yet achieved in the therapy of severe arthritis of the hip, for example, is total hip replacement, and this therapy is neither biochemical nor pharmacologic. It is biomechanical. Further studies of implant design, materials and fixation are vital to the pursuit of the aims of the Commission. Thank you.

ENGLEMAN: Thank you, Dr. Harris. Dr. Donaldson, do you have any comments?

DONALDSON: Yes, I would like to ask Dr. Harris: What is the smallest size of the unit that this type of work on implants and bioengineering could be accomplished?



HARRIS: I think that there are going to have to be individual solutions to this. The smallest sized unit I can envision is a practical unit that would consist of four or five professionals in diverse disciplines with support personnel, perhaps in the neighborhood of six or eight, clearly defined with specific objectives. A unit of that size could be quite productive in a number of these areas.

DONALDSON: How many beds would you require for the support of such a unit?

HARRIS: Again, I think that the number of beds would have to be individualized within a given unit, but it is quite possible to generate extensive information selectively with a unit that consists of 20 beds, provided that it was in an institution from which it could draw other data. I am thinking, for example, if you want to have a correlation between childhood deformity and adult disease, You can draw on the general experience of a pediatric unit that is ongoing, but which now has a focus on this particular investigation. Ten beds dealing with childrens problems and 20 beds or 15 beds dealing with the adult problems in a given area of joint disease would generate enough information to make it quite feasible. Larger would be better but the smallest was the question that you asked.

ENGLEMAN: Dr. Harris there is a widespread use of the hip replacement, with good reason. Is it your impression that the procedure is being done adequately, I don't mean in Boston necessarily, but in the country, generally. Are those who need it getting it and is it generally well done technically, are the results satisfactory?

HARRIS: I am really going to have to answer that three ways. First, in terms of the distributions. The distribution has spread very widely over the past three years and I think it is a credit to the American Academy of Orthopedic Surgeons, in the efforts that they have made, to introduce a totally new concept and a totally new technique to let us say 10,000 surgeons in a short period of time and do that overall quite well. It is much more widely disseminated and effectively so. It is also true, however, that there are a number of patients who are not being well served, it is a small fraction but the educational need and the need, not only on how to do it well, but to select out which kinds of problems should not be done locally, this need is paramount. We start a four-day course tomorrow here in Boston aimed specifically at that remaining need.

ENGLEMAN: Well, thank you very much. I want to remind any of you who have not been able to present testimony that your written testimony will be looked at seriously and will be included in the volume of public testimony which will be forwarded to Congress. In behalf of the Commission, I want to thank all of you for your attendance, especially to those of you who made these very splendid arrangements for this hearing. Thank you very much.

S U B M I T T E D   S T A T E M E N T S

BERNICE R. SPEEN  
Brookline, Massachusetts

I am Ms. Bernice R. Speen of Brookline, Massachusetts, submitting testimony on behalf of the Massachusetts Arthritis Foundation. I am an elected Commissioner to the Brookline Housing Authority and serve my community in many civic and philanthropic endeavors. Today I am presenting my testimony as a mother who unfortunately has experienced much frustration while her child suffered from juvenile rheumatoid arthritis. My story must be told because pediatricians in Massachusetts, though well qualified, have had a minimum amount of experience and training in dealing with JRA. Adequate facilities must be made available to meet this need. My story is self-explanatory.

Arthritis is not only a potentially painfulcrippler of young and old, it is occasionally fatal, even when the patient is afforded the best medical treatment available. My son Jerome - Jerry - was 4 1/2 years old when he was first diagnosed as having juvenile rheumatoid arthritis, perhaps the most common of all childhood diseases, but one which I knew nothing about until Jerry was stricken with it.

My story is really Jerry's story, since no eulogies are written for five-year-olds, pure and innocent children. But Jerry's life was not snuffed before he was able to contribute to the needs of society. Even at this tender age he was an exceptionally giving child who loved and made happy of all those around him, asking only in return for protection and guidance of his family, his mother, his father, his older sister, and his older brother. Every life deserves purpose and respect and I would hope that Jerry's death might serve a purpose and a respect through this testimony.

Jerry was attending nursery school in March, 1965 when we were visited by a close cousin, a nurse, from Mt Sinai Hospital in New York. It was she who happened to notice Jerry's condition and brought it to our attention. She noticed Jerry limping and when she touched his foot she was aware that there was something wrong with his ankle and it was out of proportion to the touch that she gave to it...he also dragged it a little. She suggested that we go immediately to a pediatrician.

When we took Jerry to the pediatrician, he said, let's wait and see, and he thought maybe a child in school had kicked him.

We began a series of visits to doctors because Jerry had chronic complaints. It soon became obvious that he could not handle going to school. Two weeks after we returned to the pediatrician, he suggested taking Jerry to a well-trained pediatric orthopedic surgeon in Boston. Like the pediatrician, he just said wait and see.

Meanwhile, our pediatrician made it known that he regarded my husband and me as alarmists and overly concerned parents.



Over the next few weeks, Jerry developed high temperatures, stomach aches, a cough, and felt great discomfort. The pediatrician diagnosed a virus. Finally, when Jerry's temperature rose to 106 degrees for two days, we rushed him to the Beth Israel Hospital Pediatric Ward.

Within 24 hours he was able to confirm the diagnosis of juvenile rheumatoid arthritis. At that point, finally, treatment was initiated to relieve our very sick child. Fortunately, the chief of staff had studied this disease, not in the United States, however, but in England at a hospital which at that time was one of only three centers doing research for juvenile rheumatoid arthritis in the entire western hemisphere.

He was aware of one of the centers for juvenile rheumatoid arthritis which luckily was in Boston at the Robert B. Brigham Hospital, and with our consent called in its Director of Clinical Research, Dr. J. Sydney Stillman, as consultant.

Dr. Stillman made a careful examination of Jerry, concurred with the diagnosis, and gave us the reassurance and information about the disease that we so urgently needed. When Jerry was discharged from the hospital 2 weeks later, Dr. Stillman accepted him as his patient. He saw him monthly, observing the effect of aspirin, quiet play, no school, and a home free of anxiety. Every morning, Jerry had to have a warm shower since it took him at least 2 hours to relax his stiff and wretched body. I kept a record, with the help of our pediatrician who visited him weekly, of his temperature, pulse, heartbeat, rashes, behavior, and other unusual symptoms. This was to aid Dr. Stillman's research program at the Brigham. Our other two children who were 11 and 13 at the time were made aware of their brother's problem and they became part of the medical team helping him. Jerry was on this schedule for 7 months. Then, early November, one week after his fifth birthday, he developed a severe attack with a fever that mounted to 107 degrees, lasting 3 days.

He died 13 days later on Thanksgiving Day, with the same nurse cousin in attendance, flown in from New York because no one wanted to special a dying child. Although it was in conflict with our religion, we felt that more questions had to be answered about Jerry's death.

We allowed an autopsy to be performed. Jerry had been an active, healthy lovely child for 4 1/2 years and we felt that we owed to other families whatever bits of information about the disease that could be learned from Jerry's research. There was also some medication that might have been able to be used had it been put in pediatric form. It was not made available, unfortunately, and therefore, we could not have used it.

Coincidentally, my son's death occurred at the point at which the least amount of Federal dollars were made available for research grants.

I hope all of you know that arthritis can strike anybody at any social or economic level. Most of us, unfortunately, are not aware of the severe problems that it can cause until it happens to strike us personally. When it hits us or our families, only then does it provoke our interest and action.



I am tragically aware of budget problems in medical research and I hope that this problem can be licked.

To help the Brigham research effort, I established the Jerry Fund in honor of my son with the donations put to immediate use on behalf of all the sons and daughters who today must suffer because of lack of adequate research to find the cause of this terrible disease.

I sincerely urge that maximum funding be allowed for research and training in the field of arthritis and hope that this testimony will be one more way of proving that need.

Thank you very much for the opportunity to present this written testimony. I have been called out of town to represent my community in the housing effort and would have rather met you personally.

TONDA L. OLSON  
Boston, Massachusetts

October, 1975

I was 13 years old at the time I experienced excruciating pain and swelling of the joints in both feet and left shoulder to the point I was unable to put on shoes and my arm froze in an upright position. This was a mystifying and bewildering experience as I had excellent health during my developmental years, was physically active, aggressive and competitive. My hometown physician was able to narrow down the symptoms but referred me to an internist in my state whose specialty was arthritic diseases who determined that I had rheumatoid arthritis. I can recall that it was very difficult for me to accept I had a disease which placed certain limitations upon me, especially at a critical stage of my life when my family had just moved to this town only 4 months prior and I was entering my freshman year in high school. I fought very hard to maintain an image in my own mind that events in my life were unchanged and that I was no different from my peer group which resulted in superficially taking care of myself and frequent heated discussions with my parents to take better care of myself.

The first two years of high school my activities were greatly restricted and the only extracurricular school program I was allowed to participate in was as piano accompanist for the Glee Club. My athletic interests were off limits. During high school and college years there were the following areas of conflict: 1. The restriction of my activities; 2. As a result of restrictions, the lack of self-confidence in developing interpersonal relationships; 3. Being an only child whose parents were greatly concerned about my physical health; 4. Not being able to seek part-time employment as did my peer group and feeling anger when asked by others if I was living at home (meaning being supported by my parents) or if I was working.

During college the internist whom I learned to trust and confide in left his practice and referred me to another physician. I was disappointed and never developed the same trust relationship as I felt I was secondary to his existing case load. As a result I stopped going to him.

A year after graduating from college I developed difficulty walking. I was evaluated by an orthopedic surgeon who had treated me previously in conjunction with my first internist. He recommended surgery. What followed was an extended hospitalization period of 6 months duration for metatarsal head resection of both feet at the same time with injection of both heels to reduce spurs, two weeks later a metacarpal head resection of the the right hand, and then a prolonged period of treatment for a staph infection of the right heel resulting in two skin graftings. I had much bitterness and resentment following the hospitalization concerning the necessity of all the surgery and the appropriateness of major surgery on both feet rather than one at a time.

It became clear that it was important to be followed by an internist who could help balance and put in perspective the role of the orthopedic surgeon as far as the need for corrective surgery.

Ten years ago I was unaware of the Robert Breck Brigham Hospital as a specialty and teaching hospital for arthritic diseases and no physician by whom I was treated ever suggested the hospital as a diagnostic and treatment center. Concerned that I needed consistent and comprehensive treatment, my father wrote to a college professor at Rutgers University who had an article on juvenile rheumatoid arthritis in a popular magazine requesting him to provide us with names of physicians Olson in our area whose treatment specialty was rheumatoid arthritis. This roundabout process led to requesting an interview and evaluation at Robert Breck Brigham Hospital with Dr. J. Sydney Stillman in 1966 and my continued treatment with this hospital. My experiences with RBBH and in particular Dr. Stillman have been very satisfying.

My basic concerns lie in the area of education of the public but in particular families and the person with any type of arthritic disease to understand and be able to emotionally deal with all aspects of the disease. I know I still have suppressed anger as to why it had to be me that has arthritis.

Tonda L. Olson, age 32, single. age 32 single I am employed as a psychiatric social worker at the Augusta Mental Health Institute

JOSEPH W. BOUDREAU  
Lynn, Massachusetts

September 25, 1975

Prior to being introduced to Dr. Arthur P. Hall, and the Robert Breck Brigham Hospital, I needed crutches and a cane or both. In the past I had been treated by a local physician for rheumatoid arthritis. The results were minor to zero. After a period of five weeks at R. B. Brigham under Dr. Hall and his staff for treatment and therapy as well as counsel, I was discharged. I left the hospital unaided. I am on a prescribed schedule of physical therapy, gold injections and medication. I visit the outpatient department on a regular schedule, and I am physically and mentally at ease. I strongly recommend any person of any age who suffers from this disease to have their family doctor request admission to the R. B. Brigham Hospital, or hospitals which specialize in arthritis and musculoskeletal diseases.



JOHN AND MARY FURLONG  
Hingham, Massachusetts

Our daughter, Ann Furlong, age 4 1/2 was stricken with juvenile rheumatoid arthritis December 1, 1974. The initial symptom was a grave swelling of her knee when awakening in the morning. Immediately I called our pediatrician who examined her, ordered X-rays, noted fluid on her knee and told us he would consult with other doctors but to give it a week. Meanwhile, our daughter was not able to walk.

After much calling and begging for help our pediatrician arranged for us to see a pediatric surgeon at one of the most prominent hospitals in the Boston area. He in turn referred us to an orthopedic surgeon who admitted her to the hospital, aspirated her knee in the emergency room and ordered intravenous feedings of antibiotics because at this time they were not sure of the diagnosis. This was a most traumatic experience for our daughter because she was continually visited by groups of doctors who examined her rather painfully at times. Finally after the diagnosis of J.R.A. was made we were told that our pediatrician would be the person to treat her. This was the man who totally rejected our suggestion that maybe our daughter had arthritis in the first place. However, we did agree to have her come under his care but became increasingly frustrated as nonmembers of the medical profession when our pediatrician could not agree with the orthopedic surgeon as to whether our daughter should be on her knees at all when they were inflamed. After several visits to our pediatrician because Ann was having side effects from aspirin taken every 4 hours round the clock and because she had become totally incapacitated as well as extremely whiny, we requested a consultation with a rheumatologist. Also, at this point I might add that we were sitting with her all her waking hours and this became rather trying with our other children. Our doctor, however, thought our request was sheer nonsense and refused to recommend us to anyone so in sheer desperation we called the Arthritis Foundation. I can't explain their kindness to us. At last there seemed to be a ray of hope. They forwarded information about J.R.A. as well as sending a list of rheumatologists in the Boston area. You cannot imagine what a consolation this was to us as previously when we requested such information from the doctors it was denied. Thereupon we called the Robert Brigham and were seen in the J.R.A. clinic where my daughter had a total evaluation and was treated with such kindness as a person with a disease and not just a disease itself. Aspirin was prescribed for her, a certain period of total rest and a series of exercises and splints. Fortunately she has progressed and had a very comfortable summer.

However, we do feel that because of J.R.A. our daughter who was once a very happy laughing child has become a very dependent child at times, as well as an extremely whiny child who often awakened two or three times a night. But I guess this is characteristic of people who are uncomfortable.

We have encountered a great deal of ignorance about J.R.A. Unfortunately the picture most people have of arthritis, unless they have someone severely afflicted, is the picture of the woman on television popping an aspirin in her mouth for the relief of arthritis and lo and



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behold she is cured. This image seems to be prevalent even in the nursing and medical profession as apparently some of these people have never seen a child afflicted with J.R.A. Schools likewise do not seem to be aware of J.R.A. but at least in our case we have found them to be open and cooperative. Education seems to be the answer here.

As far as the social impact goes, our daughter has not been severely affected because of her age. However, it was very upsetting for her not to be able to run and play with the other children when she was very uncomfortable.

We believe strongly in research programs and funding for arthritis. In fact, my husband and I and our other children as well as some of our relatives have partaken in research studies at the Robert B. Brigham to aid in the discovery of a cause and cure for arthritis. We sincerely hope the government will see fit to fund programs of research for the detection and prevention of this dread disease.

ORLANDO E. VITULLO  
Providence, Rhode Island

September 30, 1975

The estimated prevalence of arthritis in Rhode Island is 237,000 persons who have some arthritis of whom an estimated 94,000 have the disease severe enough to require medical care. It is also estimated that an additional 2,850 Rhode Islanders become arthritics each year. The estimated cost to the economy of Rhode Island is over \$40 million each year because of arthritis. These diseases are a definite drain on Rhode Island's dollars, human energy and morale, and may have a causative bearing upon the high unemployment rate which this state has been subjected to.

The Rhode Island Arthritis Foundation has been involved in home care services to homebound arthritis patients since 1952. We provided physical therapy, occupational therapy and nursing care to the arthritis patients of local referring physicians. Up until 1968, this Chapter was the major source of physical and occupational therapy for homebound patients because the nursing agencies provided nursing care only. With the entrance of Medicare, and the requirement for home health agencies to provide an additional service, the Visiting Nurses Associations included physical therapy among their services. At that point in time this Chapter began a gradual reduction in home care services and we terminated our home care program this year. We intend to use our resources to improve the ability of nursing agencies, which are geographically deployed about the State, to handle some of the problems.

Our new program will concentrate on public and professional education. We feel that this program will fill definite needs in arthritis, namely, to educate the public and the medical profession that arthritis is a manageable disease. Since we also feel that the patient has a major role to play in the management of arthritis, we intend to organize so that we can provide him with the education he needs to play that role.

Most of the "arthritis" diseases are chronic. This means that once the disease sets in, it usually continues for years or for life. It also means that one does not "heal up as good as new" but that whatever damage takes place remains permanently, and tends to get worse unless properly and continually managed.

But, since these diseases are not always at an "acute" stage, the patient is seldom hospitalized. Therefore he spends most of his disease-time at home where he is away from direct medical services and supervision. Under such circumstances, "continual management" of the disease now becomes a function of the patient himself. Without his cooperation and participation in his own care, "proper" management of his disease can soon become a questionable item.

One answer is to educate the patient so that he has the ability to cooperate and participate with his physician. He must be trained if he is expected to play his role. He needs to know exactly which rheumatic disease he has, what he can expect, how he can help, what things are generally helpful and which are not, what local resources are available to him and how he must go about them, etc. He also needs to know about the various practices of the quacks and charlatans and he needs to be cautioned against the various drugs and gadgets they offer. Without such knowledge it is doubtful whether patients can become sufficiently motivated to actively participate over the long term which may be required.

The patient's best source of specific and general information is from his personal physician. But, unfortunately, most physicians are too overworked or overscheduled to have the time to thoroughly educate their patients.

As a consequence it is not unusual for a patient to leave his physician's office without the depth of knowledge he needs to become an active participant in his own management program. It is not uncommon for such a patient to seek out information from friends and neighbors, and he may even fall victim to a fast-talking quack without being aware of the dangers to which he may be subjecting himself.

There is little doubt that large numbers of arthritis specialists and researchers must be trained if we ever hope to conquer the arthritis diseases. But since it is still customary for people to select "family physicians" to serve their general health needs, up-to-date diagnostic and management techniques must be taught to the entire medical population. Without such knowledge, much arthritis may go undetected in its early stages when it is best treated.

America has only 2,200 rheumatologists (physician members of the American Rheumatism Association and who are primarily concerned with the treatment of the rheumatic diseases) and there are over 20 million Americans who have arthritis severe enough to require medical care.

If these rheumatologists were ideally deployed around the country so that each could care for his "share" of the total patients, each physician would have 9,100 arthritis patients to treat.



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With such a patient load, if he worked a 10-hour day, 6 days per week, the physician could give each of his patients only one 10-minute treatment every 6 months.

Unfortunately, rheumatologists and their patients are not so "ideally grouped." Some regions have many rheumatologists while other regions have very few.

Under the circumstances indicated above, it is obvious that many arthritis patients are not being treated by rheumatologists but are receiving their care from the orthopedists, general practitioners or others. Unless a broad program of medical education is instituted to cover up-to-date diagnostic and management techniques for the large number of physicians who are not rheumatologists, much arthritis may continue to go undetected in its early stages and crippling may continue to be the destiny for many Americans.

With a concerted program of public and professional education in arthritis, an educated public and an educated medical community can close many of the gaps in the detection and management of the arthritis diseases through their cooperative efforts. As fast as researchers uncover new methods, such "patient-physician-AHP" teams can put them into practice for the benefit of the patient.

MR. AND MRS. LEON MANKOWSKI  
Greenfield, Massachusetts

October 3, 1975

We have just learned of the hearings to be held in Boston by the National Arthritis Commission on October 15, and although we are unable to attend, we want to express our sincere interest in any Federal health program that will help to carry on research and to bring information to the public regarding arthritis and related diseases.

We are parents of a 23-year-old girl who has fought the pain and crippling of juvenile rheumatoid arthritis since she was 8 1/2. As a patient of Dr. J. Sydney Stillman and the Robert B. Brigham Hospital in Boston, we feel that she has had the best and most knowledgeable treatment available. But this was not enough to stop the advancing destruction by a disease about which little is known or understood by the general public.

Until the summer of 1961, our Jeannie had led a normally active life. Swimming, skiing, skating, dancing, piano lessons, and scouting activities occupied her after-school hours. Our family vacations were spent camping. All of this suddenly ended after she awoke one morning with a scream of pain as she tried to straighten her knee. In less than an hour we were in the local hospital where after tests and X rays, we were told that it was "probably a little children's arthritis." We had never heard of such a thing, but when we were later referred to Dr. Stillman, we learned that indeed many children suffer from juvenile rheumatoid arthritis.

The years that followed had some hopeful periods, but others were filled with pain and frustration. As the disease spread to other joints, Jean became confined to bed and wheelchair. For four years she studied



with a home teacher and spent the summers in the Robert Brigham Hospital for treatment. During this period she had little contact with her old school mates. Children tend to keep busy with their own affairs, and neither they nor their parents understood why Jeannie was unable to carry on normal activities. She "looked" healthy. And, like us, they had never heard of J.R.A. Many people, including our own relatives, thought we were pampering Jean, and that her illness was "in her imagination." How could they think that a child with her zest for everything would choose inactivity. Others stayed away because "it made them feel badly to see her."

Finally Jean was outfitted with braces, but because our local high school was inaccessible, she attended a neighboring town where the building was designed with ramps. Our days began at 5:30 a.m. in order for her to have her exercises, eat, dress, get into those long-leg braces and be driven the 12 miles to school. Entering a new school after four years of near isolation was a strain both physically and emotionally, but she made new friends and entered into as many activities as possible. These were necessarily limited because of her disabilities and also because of the need for extra rest.

In January, 1970, Jean had a knee arthroplasty. She was determined to go away to college without braces. The surgery itself was an apparent success, but a flare-up followed, and she was forced to complete her studies at home and was unable to attend her high-school graduation. During the next three years the arthritis seemed to find every joint in her body not already affected. The pain was intense. Often she could not move in bed without help, and was on a liquid diet which she took from a straw because her jaws hurt too much to eat. She could no longer hold a pencil to write, nor a book to read. She could not feed herself, had no appetite and became very thin.

As parents, we have seen other girls going to proms, dating, marrying, and having children; or going away to college, traveling, and pursuing interesting careers. We have learned to listen to the exploits of our friends' children and be glad for them. But always there's that awful inner hurt that our own child cannot share this or that experience. On occasions when we took her out, the standard questions were "Did she have polio?"; "Skiing accident?"; "Automobile accident?" And when we explained that it was rheumatoid arthritis the skeptical reply was "I thought only old people had arthritis," or "Is she in any pain?" And everyone had heard of a sure-fire cure for arthritis. The television advertisements offer relief of some sort at least once every hour of the day and night.

Our twelve-year-old son has not been untouched by his sister's illness. His activities have often been curtailed, depending on her needs or condition. But he has developed an awareness and understanding for the handicapped which few of his age possess.

Finally the arthritis has quieted again. Since June, 1974 Jean has had a total elbow replacement, arthroplasty in both ankles, and knuckle replacements in both hands--a total of eight operations, all done under local anesthesia because of difficulties in administering a general anesthesia. A few friends have seen beyond the scars and deformities and

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have accepted her disabilities for only what they are. They have learned her limitations and are sensitive to her needs. This social contact is filling an important facet of her life which was missing when she was confined to home and family.

In September, Jean enrolled for classes at the Community College in our town. She still has to depend on help to dress, and be transported to school, where she must ask fellow students to push her chair between classrooms. But she is adjusting well and is hopeful of yet becoming independent. Her family and friends pray this may happen. Still we must face the painful reality that the disease may again become active and end even these limited activities. For there are days when the usual pain and stiffness become more intense, movement more difficult. At such times there is between us the unspoken fear that this may be the beginning of another "flare up." And always, continued physical therapy is a part of the daily routine.

Somewhere there has to be a cure for rheumatoid arthritis. Research can help to speed the day when it is found. And public awareness and knowledge can help make life a little easier for the afflicted ones in the meantime.

DENISE DE SISTO  
Peabody, Massachusetts

October 1, 1975

I am writing in a recent request by Dr. Stillman of the Robert Breck Brigham Hospital, Boston, to help in the research of arthritis.

In February of 1974 my son, Michael, age 3 years, woke up from a Saturday afternoon nap and could not walk. At first I thought he had just bruised his left knee or some other minor injury. The next day he still could not walk so I took him to my pediatrician. He had no fever or swelling in his knee at that time. My doctor admitted him to a children's hospital in my area. He told me that Mike had either rheumatic fever or rheumatoid arthritis. By the time I got to the hospital he had a fever of almost 104 degrees and his knee was beginning to swell. That night they took a series of X-rays and put his leg in traction. At this time an orthopedic doctor was called in for consultation. Michael's leg stayed in traction for about 5 days. During that time he ate very little and was beginning to become depressed about the situation on the whole. After the traction they decided to put his leg in a bi-valved cast. This was kept on all the time except when a therapist came twice a day. She was supposed to teach Mike how to walk with crutches. They also ran a series of blood tests. One day I went to visit him he had a band-aid on every finger and one on each arm. This upset Michael very much. Once they used a needle to relieve the pressure and swelling from his knee. He was in the hospital for about another two weeks. He was still in pain and his conditions had not improved. The therapist continued to come twice a day until finally Mike started to scream when she would insist on him walking. He told her that his knee hurt too much to walk on it but they insisted that he could not go home until he learned to walk. They decided to give him aspirin to help the pain, so 4 times a day he was given 6 children's tablets. When this started to upset Mike's stomach the nurses would give



him milk to help his stomach. By the third week Mike had lost about 10 pounds and this would make him weigh in at about 30 pounds. My doctor finally told me to take him home.

When he got home his personality improved and he started to be himself again. The inflammation began to spread so that Mike's doctor suggested taking him to a specialist. This is when we got in touch with the JRA clinic at the Robert Breck Brigham Hospital.

It was here that he got the best and most desirable help available. The doctor we saw started Mike on placquenil and regular therapy sessions. The therapist stressed to us not to allow him to walk because this was only aggravating his knee even more so. She taught Mike the exercises to do and he slowly lost his fear of the doctors and nurses at the hospital. By June he could walk with only a slight limp and at present he can run and play with no trouble at all. It happened so quickly that his recovery seemed almost like a miracle.

I am very grateful to all the people at the Robert Breck Brigham for their help and for their patience with Michael. I am glad that a hospital of this kind exists for people of all ages to go to for help with such a devastating illness.

I hope I can help in some way to eliminate such a dreadful illness and to help in wiping it out.

I intend to be there on October 15 with Michael and my husband.

I hope something can be done to make people aware of this illness because I must admit I did not know it would affect children until it hit close to home.

SALLY S. CAROLINE  
South Hampton, Massachusetts

My daughter Rebecca (age 5 years, 4 months) was diagnosed as a victim of juvenile rheumatoid arthritis at age 3 years, 3 months and was accepted as a patient at the Clinical Research Center for Juvenile Rheumatoid Arthritis at the Robert B. Brigham Hospital 2 months after the initial diagnosis. We were extremely fortunate to receive an early diagnosis and immediate treatment--especially from a very dedicated and aware ophthalmologist--and to have access to the staff and facilities of the Robert B. Brigham Hospital.

The major problem we face is a severe and persistent uveitis--one of the presenting symptoms in Rebecca's case--which has never been fully controlled, despite treatment with every available medication from cortisone to atropine. There is some optic nerve damage and glaucoma, and the level of inflammation fluctuates so wildly that it is impossible to prescribe corrective lenses. Her vision has been measured at 20/80, 20/400, and everything in between. Any number of ophthalmic consultations, both through the Robert B. Brigham Hospital and the Massachusetts Eyes and Ear Infirmary have only affirmed that everything possible is being done.



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We are assured that at puberty, uveitis almost invariably ceases to be a problem for JRA patients, but there is no assurance that Rebecca will have any usable vision by that time. The doctors' hands are tied; their arsenal of weapons against uveitis is too limited. We fight with everything available, but it is not enough.

Too many people think of arthritis as an "old people's" disease, a disease that makes joints ache. There needs to be much greater public awareness that rheumatoid arthritis doesn't just hurt--it cripples both young and old, and it can damage much more than just joints. It can even blind a child...my child, and how many others?

WALTER S. REED, JR.  
Boston, Massachusetts

October 2, 1975

Dr. Theodore Bayles asked me to write a short letter on the history of my recent arthritis attack.

I first noticed a swelling in my left toes in early May 1974. This quickly spread to my right leg, causing difficulty in getting up and down. By mid-May I was under treatment by a local doctor, and it was diagnosed as rheumatoid arthritis.

The swelling and pain continued and spread, effecting both my feet, the right knee, both hands and lower arms. I was put under Dr. Bayles's care in late June '74 and admitted to the Robert Brigham Hospital on July 2, 1974. By this time I could not walk alone, could not light a match or lift a coffee cup.

After twelve days' examination in the hospital I was put on the following medication: 15 grams of prednisone, 2 plquenil, and 16 bufferin daily. I followed this routine to the letter and started reducing the amounts as directed by Dr. Bayles. At the present time I take 1 Plquenil and two bufferin each morning and two bufferin each evening.

I have no aches or pains except in my right foot early in the morning before the bufferin have taken effect. I have complete use of arms, legs and feet, however one toe on the left foot is slightly bent and will not straighten. I do notice I get tired a little sooner than before this attack, but am able to do nearly everything as before.

ARNOLD P. ROMANOWSKI  
Westford, Massachusetts

September 27, 1975

I am Arnold P. Romanowsky, 62 Dunstable Rd., Westford, Mass. 01886. My age 63, married and living with my wife in our own home. I have rheumatoid arthritis, and it's been with me for more than twenty years. I have managed to keep active with the help of medication and my chiropractor.

In the last three years my condition became worse. I was unable to walk or to lift anything. I had to leave my job.

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On the advice of my doctor I was admitted in Robert B. Brigham Hospital, Boston, Mass. Two weeks and four days later I was discharged, walking normal and able to do light work, but not strong enough yet to return to my regular job.

What the doctors and therapy have done for me while I was in the hospital was practically a miracle.

I hope they continue the good work, and a cure must be found, research must continue.

DOROTHY B. BURNHAM  
Boston, Massachusetts

I did not get notice from the Robert Brigham Hospital soon enough for me to be able to attend the meeting of October 15, 1975, at John Hancock Hall in Boston.

I had an operation giving me a new plastic hip bone and metal bass and socket in July 1974. It was never done until 1969.

It hurt me every step I took. Now, a year later, I even walk stairways and five blocks every day. They could promise me that I would no longer have pain.

I think it is good to have research on arthritis. I have seen fingers repaired for use and also feet corrected that would walk after treatment.

The Robert B. Brigham Hospital is finding new ways to help people. I have a friend who can now walk out. There still needs to be more research in all kinds of arthritis. It is torture to see some who can't be helped very much at present.

My trouble is osteoarthritis. My mother had arthritis of the spine. They could only keep her alive five years afterwards when I was more fortunate.

DWIGHT R. ROBINSON, M.D.  
Boston, Massachusetts

October 15, 1975

One of the pressing needs for the alleviation of the suffering of nearly all patients with arthritis in its many forms is for the development of more effective chemotherapeutic agents. Although a large number of therapeutic agents are available, many in the category of anti-inflammatory drugs, they are often of marginal effectiveness and have the disadvantage of significant toxicity, which can lead to occasionally life-threatening as well as more frequently, annoying symptoms. One of the difficulties in the rational development of pharmacologic agents for the treatment of rheumatic inflammatory diseases is the lack of an appropriate in vitro test system to screen potentially therapeutic compounds. The complexity of inflammatory reactions in rheumatic diseases as well as other conditions also contributes to the difficulty of rational approaches. Many of the tests utilized involve experimental inflammatory

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reactions in animals which may bear little resemblance to the processes which occur in the human diseases.

Our own laboratories in the Arthritis Unit at the Massachusetts General Hospital involving several members of our Unit have concentrated recently in the use of cell and tissue culture systems utilizing tissues from patients primarily with rheumatoid arthritis removed at surgery. It is our conclusion at this point that the development of these in vitro techniques may contribute significantly toward the search for a more rational pharmacology in the rheumatic diseases. The isolation of specific enzymes and mediators of inflammation, a better knowledge of their biosynthetic and regulatory pathways and the characterization of specific cell types in rheumatoid and other diseases which may be responsible for their manifestation should provide important knowledge as a background for pharmacologic research. It is our opinion, Mr. Chairman, that the support of research in these areas by new programs in the fight against arthritis offers considerable promise of the development of major advances in therapy of not only all of the inflammatory rheumatic diseases, but for the inflammatory aspects of osteoarthritis and related disorders as well.

MRS. BENJAMIN BLESOFF  
Medford, Massachusetts

September 28, 1975

Gentlemen: I am unable to testify because of my arthritis but I strongly urge the Federal government to make it possible for the medical profession to receive the necessary help to do more extensive research so that the millions of arthritic sufferers may find relief and hopefully a cure in the not too distant future.

EUNICE WILSON  
Coventry, Rhode Island

October 19, 1975

I wish to express my views concerning the needs of persons afflicted with arthritis.

I am a registered nurse employed by the Rhode Island Arthritis Foundation.

I make home visits to patients who have been diagnosed rheumatoid arthritis or some other rheumatological disease. One of the greatest needs for arthritic patients from my viewpoint is education. This education should be for the professionals as well as the public. I do not feel that there is enough knowledge about arthritis among the practicing physicians in order to guarantee good health care to persons diagnosed with arthritis. If the professional or some allied health person isn't available with the necessary answers for proper treatment, etc., then all of the public education is worthless. The professional is the one doing the treating; we frown upon self-medicating and self-treatment. If the medical doctor is too overworked to handle all of the teaching for arthritics, then perhaps referrals to those persons qualified to answer



the questions and advise proper management with the M.D. as the diagnostician and overseer, is the answer.

Another aspect to the needs of the arthritic is the problem of rehabilitation. The patient does not have any place to turn for the help they need to return to a productive life. A centrally located facility which could provide information concerning their disease as well as a rehabilitation center to help them to overcome their handicap would be a great help.

We consider the physical impact constantly when we think of helping someone. I feel that the psychological side of any chronic disease is just as important. I believe if we consider any educational or rehabilitation center to assist the arthritic we also have to consider having someone available to whom the patient can relate and talk to with their problems. I have found that my patients regard me as someone special. Not because I am, but rather because I deal with arthritics and they feel I understand better than the nurse who deals with all types of illness.

I hope this letter will be beneficial for the Commission dealing with the problem of arthritis.

THEODORE B. BAYLES, M.D.  
Boston, Massachusetts

There are many aspects to the important problems of rheumatic disease research and clinical care of the patients. I have been involved in all of these areas for over thirty years and particularly involved in the problems of postgraduate education in rheumatic diseases, primarily through teaching medical students, interns, residents and postgraduate fellows at the Peter Bent Brigham Hospital and the Robert B. Brigham Hospital since 1945.

In addition, we have provided week-long courses for the American College of Physicians on three occasions with students coming from most of the states and adjacent foreign countries. While this experience has been very worthwhile and interesting, I think my experiences are best rounded out by the fact that since 1941 I have had a busy and egalitarian practice which has given me a rather complete interface with the problems that patients of all classes, types and colors encounter in trying to find adequate care for their rheumatic disease problems.

Patient after patient tells of the number of doctors he has seen and the apparent lack of any real basic information as to the arthritic disorders and in many instances what to do about them. Dr. A gives anti-inflammatory drugs 1 and 2, Dr. B gives two other inflammatory drugs and Dr. C. starts them on the dangerous and unproductive program of cortisone therapy in some form. When the patient or the doctor becomes frightened of the medicine, then through him or some friend the patient consults a rheumatologist such as myself. In many instances the patient by this time has had considerable progression of his disease and there may be irreversible changes in the joints which cannot be undone.

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The other side of the coin is that even in the best hands a small proportion of patients cannot be improved and continue a relentless and devastating downhill course. This points up the continuing need for adequate and good support for basic and clinical research in rheumatic diseases.

As a result of these observations, I would feel that since there may never be enough rheumatologists to take care properly of all the patients with rheumatic diseases in our country, it seems better to spend a lot of money, time and energy in providing better and more complete training in rheumatic diseases in our medical schools, residency programs and postgraduate medical education along with parallel education for the paramedical personnel, such as occupational therapists, physical therapists, social workers and specially trained nurses and medical assistants.

Having worked in a general university teaching hospital for thirty years, I have seen the difficulties in trying to give good care to rheumatic disease patients in an excellent general hospital when the patient with chronic and non-critical disease, such as arthritis, has to compete with the patient in the next bed for the attention of the physician when his neighbor has an acute myocardial infarction, lobar pneumonia, bleeding ulcer or some acute medical problem. In the general hospital, to put it bluntly, the arthritic patient gets lost in the shuffle and cannot compete for proper care and consideration in the average general medical service. This points up the special need there is for either a separate facility for rheumatic disease and other chronic patients in the general hospital or a special institution, such as the Robert B. Brigham Hospital, which can devote all its energies in the care of the patient and is a model for other institutions to follow.

In conclusion, I would appeal to this Commission to make a strong recommendation to the Congress in favor of greatly strengthening and expanding the educational programs for arthritis in the medical schools and postgraduate training at all levels in all the institutions involved in preparing the physician for his professional career. I am sure that the outstanding individuals on the education panel can provide proper and useful programs for your report to the Congress.

JOHN A. MILLS, M.D.  
Boston, Massachusetts

October 15, 1975

The clinical presentation of serious musculoskeletal and other connective tissue disease is frequently obscure or misleading. Furthermore, complications of such diseases may involve almost all organ systems and are often the immediate causes of death. The education of physicians regarding the broad spectrum of these manifestations should be an important objective of the National Arthritis Act.

Because most patients with undiagnosed rheumatic disease present to general practitioners, internists, or orthopedists, an increased awareness



of, and interest in the clinical features of these diseases should be a part of any training program in these basic disciplines. In order to accomplish this objective, rheumatologists and orthopedists with a broad knowledge of the clinical aspects of the musculoskeletal diseases must be trained and made available in the larger community, urban general and university hospitals to stimulate and maintain this important clinical orientation. Only in that way can treatment or referral be instituted at a time when the later complications of disease might be prevented.

In the past, financial support for clinical teaching has been derived directly or indirectly from training and research grant funds. As these sources have become more restricted so has the option of supporting teachers and teaching through health care insurance been increasingly circumscribed. It is appropriate that the various health care activities be identified for what they are and supported in a rational way. Because it seems uniquely situated to do so, the National Arthritis Act should have as a major goal both the training of rheumatologists and orthopedists in a general medical environment and the education of other members of the several medical and surgical disciplines who inevitably will continue to provide a large and important part of the care of patients with musculoskeletal diseases.

ARTHUR P. HALL, M.D.  
Cambridge, Massachusetts

October 10, 1975

I am a second generation rheumatologist. My father was one of the first medical rheumatologists in the country. He became associated with a group of orthopedic surgeons shortly after World War I, an era in which most patients with arthritis received their care from orthopedic surgeons. I am still seeing some of his patients, followed, between us, for nearly fifty years. Arthritis is thus, truly a chronic disease. Tremendous changes have occurred in that fifty-year interval. We have many obstacles to overcome, but we no longer have to accept a wheelchair or nursing home existence for the patient with destroyed hips or knees. The bedridden patient can now only serve as an example of neglect. Physical and financial independence are being protected or restored for an unprecedented number of arthritis sufferers. The future is no longer hopeless. The word "incurable" is becoming antique. Hope illuminates the horizon.

Now can we better illuminate the horizon and magnify the hope?

First: The patient needs to be able to find a doctor who knows something about clinical rheumatology; someone who can recognize the implications of the disease he sees and can create a therapeutic program to help the patient. It is at this point that the patient is most often frustrated. Most general and community hospitals do not admit arthritis patients and the interns and residents neither see nor are instructed in their diagnosis and care. One-third of the country's medical schools do not have a rheumatologist on the faculty. The graduates of these institutions are given no preparation for the guidance or care of rheumatic disease patients. There are, several states in which there is



no rheumatologist in the state. These are the facts which I have found to be most horrifying to those interested in care of the arthritic.

Teaching must therefore be vastly improved for students, house officers, and doctors on a postgraduate level. Such training can only be provided in a university hospital environment, where not only clinical skills can be acquired through contact with a large number of patients, but the necessary background in pathology, radiology, immunology, and biochemistry can be provided. At present, even in the institutions which can provide these assets, there is no financial support for clinical fellows to learn and for the faculty to teach them. The output of qualified clinicians is so small that in most states, the majority of patients have to travel hundreds of miles to get to a doctor who is skilled and knows that good treatment requires more than the latest, drug-house advertised pain killer. Most often he finds no interested doctor. I have patients in West Virginia, South Carolina, Florida, New Jersey, and Kansas for example, whom I care for by mail due to the absence of an interested and concerned physician locally.

Second: The patient needs good back-up assistance for his doctor. First-class orthopedic help must be available with orthopedic surgeons trained and interested in the problems of arthritis patients. This is especially true now that total joint replacement offers so much to patients with destroyed joints. Many rheumatologists are forced to send their patients to Boston, or New York, or the Mayo clinic to benefit from the assets of reconstructive surgery. More often the fact that the rheumatologist may not have seen the benefits to be derived from such surgery means that the operation is never thought of or offered. The medical and orthopedic rheumatologists need to be trained in a setting in which the close contact between them, working for the benefit of the patient, is stressed and lived by, day by day. Similar exposure is needed for the radiologist and pathologist. Good physical and occupational therapy is essential and these people must be trained and have experience with considerable numbers of arthritis patients. They can be trained successfully only at arthritis centers with good departments of rheumatology. One cannot learn about arthritis by seeing one patient a month.

If we support arthritis centers with strong departments of medical and surgical rheumatology, good physical and occupational therapy, good back-up in radiology, pathology, and forceful and imaginative research programs, what will be the fruits? Several years ago we trained a medical rheumatologist from San Juan, Puerto Rico. He returned there and became associated with a rheumatologist trained at Columbia in New York. They have since sent two orthopedic surgeons to the Robert B. Brigham Hospital for periods of six months each to learn reconstructive surgery for hips, knees, elbows, hands, etc. They have sent a number of physiotherapists here to learn the special techniques required for patients with arthritis. They now have a group which has reached the critical size necessary to provide good, comprehensive care for patients with arthritis. I can think of few cities in the United States where patients can obtain comparable quality care. The investment of energy and support in well-organized teaching centers for rheumatic disease therefore, is the means of creating eventually, efficient and capable mini-centers for the care of patients

with arthritis. Centers across the country will only be as good as the people we put in them. If we invest in centers equipped with second-rate people, we will have only second-rate care for our arthritic patients. If we equip our centers with first-rate people, the care will be first rate.

T. RICHARD QUIGLEY  
Boston, Massachusetts

October 9, 1975

1. Role of allied health professionals in the treatment and support of persons with arthritis.
2. Needs in education of allied health professionals.

The nature of arthritis, its course, and its implications are well established in various medical literature, by physician testimony, and by public testimony. Where does the allied health professional, specifically physical and occupational therapists (AHP therapist), join the treatment program and how well are they prepared to do so is the subject of this testimony.

As with the majority of chronic disabilities the AHP therapists become involved as soon as possible following the identification of the disease made by the physician. The goals of the AHP therapists within their capabilities are to prevent joint limitations, reduce existing musculoskeletal limitations, and most important to assist the individual to remain as functionally independent as is possible.

Due to the active nature of arthritis the above goals are constantly in jeopardy. The AHP therapist must continually evaluate and reevaluate to note any new areas of limitations and thus modify the treatment program. The program is comprised of appropriate exercise (active, passive, stretching, etc.) at the proper time, sufficient rest periods, gait training with the use of various forms of ambulatory aids corresponding to the physical limitation, joint-protection techniques, correct resting and working posture to alleviate joint stress and deformity, modification and adaptation of apparatus or devices to enable the person to perform without assistance or minimal assistance, and to offer support and understanding to the patient to reinforce the need to maintain the treatment program over the years.

When multiple joints are involved the treatment program becomes quite involved and time consuming. This is common. When arthritis effects multiple joints in children the treatment program is understandably modified and is more time consuming. The AHP must understand the basic manifestations of the disease process, the appropriate accepted medical treatment program, and the corresponding appropriate activity level of the treatment program.

By understanding the need for daily exercise and functional activity (i.e., gait training, transfers, etc.) during the hospitalization, our facility, Robert B. Brigham Hospital, initiated seven-day-a-week full in-patient physical-therapy coverage. This schedule is an exception to the norm. Its effectiveness was impressive. An informal study was conducted comparing the average length of stay of Medicare patients undergoing joint replacement surgery 6 months before seven-day therapy coverage and 6



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months after the new coverage was instituted. Patients undergoing total hip replacement were discharged 5 days sooner and patients undergoing total knee replacement were discharged 3 days sooner. This was approximately a 12-15% decrease in length of hospitalization. It must be pointed out again that only through understanding arthritis and the needs created by arthritis were we able to accomplish the above.

As our facility is a teaching hospital we are affiliated with numerous physical therapy and occupational therapy schools. Approximately 25 AHP student therapists pass through our hospital each year to learn the disease process of arthritis and to gain experience in treating persons with arthritis. It has been quite obvious to us that very little information or therapy techniques are provided at the college level to these students. We are presently conducting a survey of the various schools to ascertain the actual extent of didactic information within their curricula. We seriously doubt if more than 8 class hours per student in 4 years of study are allocated to arthritis. We suspect much less is afforded the students.

This appeal is made to this Commission to supply sufficient education funds to the arthritis centers to conduct ongoing programs closely linked with the allied health professional schools as well as other medical care facilities. The education program would focus upon the new graduates entering the field of practice and those therapists already practicing who have little if any experience with arthritis. It is expected that these programs would greatly facilitate the distribution of knowledge and experience from the specialized centers to facilities of general medical care and education institutions.

Thank you for your attention.

JAMES H. FAIRCLOUGH, JR.  
Boston, Massachusetts

I have been associated with the Massachusetts Chapter of The Arthritis Foundation since 1950 as a member of its Executive Board. I was President for eleven years during that time, and have been Chairman since 1971.

On the national level, I have held the position of Vice-President of the Arthritis Foundation, and have served as a standing member of several committees. I am presently Honorary Vice-Chairman of the Board of Directors.

The outlook for an arthritis patient has certainly changed for the better during the past 25 years, but much remains to be accomplished.

In Massachusetts, one of the most progressive states in the union in regard to medical care, the need for rheumatologists is pressing. For instance, in the almost 100 miles between Worcester and the New York state border, there are only three arthritis specialists to serve more than one million people in the area. Traveling 40 miles one way through the Berkshires to one's doctor can be a scenic but tiring experience for an arthritis victim, and one that would encourage or force him to stay home even when vital medical treatment is indicated.



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The 580,000 arthritis sufferers in Massachusetts represent approximately 10% of the state's population, these people need the care that increased numbers of rheumatologists and arthritis clinics can provide.

The most widespread crippling disease in the country, arthritis, affects more than 20 million people seriously enough to need medical care. These people are dependent upon only 2,200 rheumatologists who are hopelessly overworked and located in geographic pockets around the country near our great medical schools. Therefore, large areas of the country in general and Western Massachusetts in particular are left without anything resembling adequate numbers of physicians, and clinics whose specialty is arthritis.

If each of the 2,200 rheumatologists in the United States cared for a diagnosed arthritis victim, each would have a patient load of 9,000 people.

In Massachusetts there are now only about 70 rheumatologists directly involved in patient care, slightly above the national per capita average with, as I have said, the overwhelming majority of these physicians in the greater Boston area.

I believe the most pressing need in Massachusetts is for vastly increased training opportunities for physicians, allied nurses and therapists, blanket public education programs aimed at both the public and hospital administrators, and the establishment of regional arthritis detection and treatment centers to improve arthritis care essential to the fight against arthritis in Massachusetts and nationwide. These efforts would be focused on the "underprivileged" areas mentioned above, which have the greatest need.

MRS. JOHN V. CATERINO, JR.  
Boston, Massachusetts

I am writing in behalf of all people afflicted with arthritis, in hopes that the money for research into a cure for all types of arthritis will be soon at hand.

I have heard that the National Arthritis Foundation is meeting in Boston October 15th, and hope that some agreement can be found to raise the funds for research into this disease.

I have a four-year-old niece that has arthritis. Having someone as close as that with the disease I know how difficult it can be for all concerned.

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THOMAS AND PATRICIA SWEENEY  
West Medford, Massachusetts

September 30, 1975

We hope that this letter will be of help in securing the much-needed funds for research into the causes and cures of arthritis.

Following are only some of the problems we have encountered with a daughter who has arthritis.

Our daughter, Linda, had to undergo quite a harrowing two and a half months of tests, tests and more tests before we found that the trouble she had with her ankles and knees was actually arthritis. Three different doctors, two separate sets of four to six X-rays (which proved absolutely nothing) and a hospital stay of five days were needed to finally diagnose what was wrong with her as arthritis. The last doctor to see her was going to send her to Children's Hospital in Boston but when he contacted another doctor at Children's Hospital he was told that the only thing they could do there was examine her all over again and if it did turn out to be arthritis, she would be transferred to the Robert Breck Brigham Hospital for treatment. For the past seven and a half months she has received the best possible treatment, but again she could be so much better and possibly cured if there was just more research into this crippling disease. Before being stricken with arthritis, Linda was a healthy and very active little four-year-old. Now it is heartbreaking to watch her sit on the "sidelines" of so many activities, not being able to join in because she needs crutches in order to walk and move around with any degree of comfort. She cannot stand for any length of time without hurting so as a result is missing out on a great deal of her childhood.

When I brought our oldest daughter to school for the first day of kindergarten, taking Linda along also, the teacher was very much surprised to learn that Linda has arthritis. The teacher remarked that when Linda starts school next year, it will most likely be difficult for her to manage the stairs and moving from classroom to classroom. "We have never had a child enrolled in school with arthritis before so it will all be new to us, too," were her words. Needless to say, it does not leave a mother with any sense of confidence in the school systems to hear this. Why couldn't schools be better educated in the school-time care of arthritic children? Even before Linda begins school, I feel that this is one of the very first things that should be brought to the attention of school departments. Too few people realize the pain, discomfort and inconvenience of someone with arthritis.

Money is the answer to a lot of questions concerning arthritis, money for research, education and helping those afflicted with arthritis and hopefully a cure to save thousands of people from ever suffering the agony of arthritis. There have been cures for numerous other diseases, when will the cure come for arthritics? Someday? Please make that someday today. There are so many parents that feel the same way. All people with arthritis are getting the best possible care and treatment but there has got to be better methods of treatment--RESEARCH will be the answer--it has to be.

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What else can we do as concerned parents of an arthritic child? Only hope and pray that more can be done in the future, and that takes MONEY FOR RESEARCH. PLEASE.

Thank you for taking the time to read this and all others that you will undoubtedly receive for such a tremendous cause.

MR. AND MRS. JEAN L. KAESELAU  
East Brewster, Massachusetts

September 30, 1975

At the onset of our 2 1/2 year old daughter's illness, it took the family doctor, a pediatrician, and 2 hospitals, almost 3 months to make the diagnosis, JRA.

Steroids were given in excess, for 2 1/2 years, as a result, blood pressure was dangerously high for a long period of time, leading to the belief that heart surgery was necessary to correct a coarctation of the aorta.

After too much time was wasted before admitting to the lack of progress in getting her off the excessive amount of steroids, Dr. Stillman of Robert Breck Brigham Hospital was finally called in.

Through the combined efforts of the RBEH facilities, great progress has been made in the reduction of steroids, her growth, mobility, appearance, and emotional outlook. We are very pleased and encouraged with hope.

It is our firm belief that there is an IMMEDIATE need for funding research and education of this disease, for all new medical students, as well as the established physician, extending to programs for public knowledge and awareness.

HARRIET B. ROSS  
Middleboro, Massachusetts

October 30, 1975

I missed the commission when it visited Boston as I was visiting my daughter in Virginia. I have been a chronic rheumatoid arthritic for over thirty-five years. I am also a diabetic.

These two chronic sicknesses have put my back to the wall financially. I have had four hand operations, one foot, and one shoulder. Medicare Part A is wonderful for the hospital and with the help of Medex 3 for which I pay \$11.35 monthly. But Medicare Part B fails miserably. Part B pays what it "approves" then a 20 percent deduction. I have been left with a balance of \$410 to pay Dr. Shea after Medicare Part B and Medex 3 payments for foot and shoulder. After one hand operation I was left with \$150, to Dr. Millender. I have not received a final hand operation bill.

For diabetes I have to buy alcohol, cotton balls, needles, test tape, and insulin. Of the five necessary items Medex 3 will pay only 80 percent



for the needles. For arthritis I take cytoxan (\$32 per 100), Prednisone (\$11 per 100), Symmetral (23 per 100), and Iron (\$10 per 100).

I also take thyroid--three a day. Medex 3 has a \$25 deductible every 3 (cannot decipher) and a 20 percent deductible on each drug. Last month my bill was \$74.05 and final payment was \$39.24, and this goes on year after year. Arthritis forced me to retire 13 years ago and I try to survive on disability and social security and pay these bills. I still have a foot, elbow to be operated on. Please, if you have a chance to intercede for me and other chronically disabled persons, we would appreciate your efforts. On two visits to my doctor the bill was \$35 and Medicare Part B paid \$16. I was left with \$19. We are the victims of the hospitals, doctors, and the drug companies. We will go on paying year after year because we are chronic and there is no cure in sight. Thanking you in advance for whatever you may be able to assist us with medicare bills.

I also had some stomach and bowel trouble and I was left to pay \$142 to Dr. George Lewis of Boston. All they have to do is refuse the assignment to Medicare Part B and we have to pay whatever amount Medicare Part B doesn't approve of the bill.

ANNA F. YODER, R.N.

The person suffering from arthritis is familiar with pain, and is constantly seeking ways to alleviate that pain. Accompanying pain is disability, usually including difficulty in carrying out the so-called simple everyday activities of living that may suddenly become overwhelming. When you're a senior citizen living alone in a second-floor apartment and you can't climb stairs, get into or out of the tub, you can't always get out of bed or out of a chair or even operate a dial phone, your ability to care for yourself is reduced to nothing. If you're a young mother with three small children and you can't take the cap off the toothpaste, open a carton of milk, button your child's sweater, turn the doorknobs or lift a casserole out of the oven for dinner, you are constantly looking for help. You want someone who can show you that life can be different, someone who can teach you how to make it different, and someone who cares about the overwhelming burdens placed on you when you were attacked by arthritis.

While all arthritis victims are eagerly awaiting the news from ongoing laboratory research that the cause and therefore the cure to their disease has been uncovered, the immediate nature of their problems makes them look just as eagerly to health professionals who can make a difference in their lives today. It is for this reason that we plead our case for funding for innovative, community-outreach patient care programs specifically aimed at case-finding and improved delivery of services to arthritics. We need programs that will say to patients that we are interested in keeping them self-supporting and that we will teach them how to live and cope with the problems they are facing.

Numerous tales can be told of the disruptive effect of arthritis on the lives of its victims. But these tales are well known to those of us in this room. What is not so well known or recognized is that good medical care is not necessarily synonymous with good health care. Health care for the person afflicted with arthritis must be comprehensive and include specialized services provided by nurses, physical and occupational therapists, social workers, dietitians, vocational counselors, and physicians. Only in this way can we make the arthritic's life more livable and freer from pain and disability.

An innovative community-based program designed to improve the health care of an urban population is currently in its early stages in the Boston area. It is based on the delivery of services by nursing professionals, professionals who traditionally have taken a broad approach to the care of the patient and who have attempted to meet the health needs of individuals within the context of their established life styles. As the services of additional allied health professionals and consulting rheumatologists are needed to augment the program a referral network has been established. The goal of the program is to educate arthritics and their families about rheumatologic diseases and how to cope with the disruptive effects which they have in one's personal and family life. The program as it is structured is complementary to medical services delivered both at the medical center and through local neighborhood health centers.

Traditionally, specialized medical care has been a function of the medical center. One might well ask the feasibility and likelihood of the arthritis population making its way to the medical center since numerous problems of mobility, inherent in the disease process, make these trips even more difficult than for the population at large. Referrals for specialized care may not be made when indicated because there still exists the belief that you must just learn to live with your arthritis if you have it, thus the need for education on an almost individual basis to both providers and consumers.

By providing care by specialty nurse clinicians and other allied health professionals in the community, several things are accomplished. First, physicians providing primary medical care are made more aware of the role which these professionals have in improving the life of the arthritic. Second, persons who have arthritis are introduced to professionals who are skilled in helping them cope with their arthritis by making adjustments in ways of doing the everyday tasks of life, and especially by educating patients about their disease and how to live with it. Finally, a more direct line of referral exists to the medical center, ensuring that when rheumatologic consultation is indicated nurses can ease the communication of information in both directions and provide a primary care person for the patient in both settings. Thus, a visit to the medical center should become less formidable to one who is accustomed to care in the local setting.

In the existing outreach project we are currently supplying services to two neighborhood health centers, and have been asked to do the same in

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others. Resources do not currently provide for a complete program. We must continually seek innovative and cost-efficient ways to provide education to patients and health professionals. Potential areas would include the development of audio-visual materials, self-tutorial systems to supplement personal contact, and methods whereby group education could become more attractive and effective. Persons with an interest in the care of the chronically ill and in the concepts of adult education must be provided with the necessary resources to combine these two areas for the benefit of the person suffering with arthritis.

In conclusion, we strongly recommend that continuing resources for patient education and for the post-graduate preparation of nurses to provide this education be given top priority. We further recommend that this be implemented through the establishment of centralized arthritis care centers, where planning for delivery of services to both urban and rural populations can be coordinated.

RICHARD J. LYNCH  
New Bedford, Massachusetts

October 2, 1975

I am writing to you on behalf of some of my clients who are severely afflicted with rheumatoid arthritis. Although I do not claim to be an expert in this field, I have been dealing with disabled clients for over five years, and I do find that their problems do present many obstacles which are not only difficult to overcome, but very expensive. With the new laws mandating that special attention be given to the severely handicapped, I feel that a maximum effort should be made to secure individual funds for arthritic patients.

They have many unique problems, and some of these problems can really only be dealt with through an up-grading in the training skills of vocational counselors.

I feel that greater emphasis should be placed upon trying to improve the quality of life for these individuals rather than looking at their rehabilitation as strictly a case of finding some type of full-time employment for them in order to get them off the Social Security roles.

The many services required to help these people to operate independently, and the limited areas of work that they can qualify for severely limits the prospects of employment. The present medical treatment and medicines that these clients need presents a major source of worry to them, and I do not see how they can be expected to find a job which would pay them enough to live on and also cover these medical expenses. This is one of the reasons why we find that motivation is very low with these people. I feel that the main point in their rehabilitation should be to arrive at their maximum capacity (which is generally part-time work), and that they should be covered by the State or Federal government for their medical expenses.



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I have found that services to arthritic patients occupies about three times as much time as the average client on my caseload. That is due to the many emotional problems that accompany the disease. The extensive variety of services necessary, and the number of agencies that must be involved, helps, not only to multiply the problems, but to frustrate the clients as well.

Any efforts on behalf of these people would be time well spent, and would be deeply appreciated by a group of neglected handicapped people.

EITHNE MCCANN, M.D.  
Providence, Rhode Island

October 1, 1975

Working with arthritic patients for a period of about 15 years, it has become more apparent to me that the major unmet need of the rheumatoid arthritic and osteoarthritic patient is a general health education program accompanied by a program which will direct a physical maintenance plan for the patient. In general the patient is under some control with a guide to medication but in many cases they are allowed to develop major disabilities because of lack of simple instruction and directions on what they should and should not do from a physical rehabilitation point of view. I feel that a program should be available for the young rheumatoid arthritic which will help maintain the muscle status and range of motion to its maximum during the acute phase of this devastating disease, the program to coordinate with an adequate medication and laboratory coverage.

WILLIAM BLODGETT  
Maine

I am William Blodgett, Representative from District 62, and my interest is to acquaint you with L.D. 1722, An Act Creating the Maine Arthritis Task Force. As you will determine, this measure is modeled after the National Arthritis Act that was signed into law in January, 1975. This L. D. will serve as a model to establish in an organized manner, a priority system to channel a flow of outside resources that will include both money and services; to coordinate the present services within the State, both public and private; and to define the priorities and needs of arthritics of the State and other Maine citizens afflicted with chronic illnesses.

Not only will this Act in itself assist thousands of seriously ill Maine citizens but the Act will also serve as a vehicle to wisely utilize appropriate amounts of Federal dollars from the \$90 million that was

appropriated by the Federal Act of 1975. Without such an Act, the State of Maine and its citizens will probably not be able to attract any of these federal dollars.

We are all aware of this crippling disease and yet many of us do not appreciate its real impact on the citizenry and the people of Maine and on the economy of our State.

Of the more than 15,000 people in Maine who are disabled by arthritis, fewer than 4,000 of these people are seeing arthritis specialists. Each year arthritis claims about 3,000 new victims and you will note that arthritis strikes women twice as often as it strikes men. Over 5,000 Maine residents are victims of rheumatoid arthritis, which as you know is the most dangerous and most crippling form of the disease. Most of these people who are stricken are between the ages of 20 to 45--their most productive years.

A conservative estimate is that our Maine citizens in their pain and desperation waste over \$1 million each year on worthless so-called "cures."

With the increased cost of hospitalization to our Maine citizens, we can no longer afford the luxury of continuing this practice of no planning. In 1973 the Maine Hospital Data Service reported that 1,003 people were hospitalized for arthritis. The average stay for these sufferers was eight days. The average bill was \$660.00.

During the year 1974 the same data service, which services 43 hospitals, indicated that the numbers hospitalized increased by more than 10% while other diseases increased by less than 1%. The costs increased to \$771.00 for the average bill. Because of over-the-counter-self-treatment and outpatient care for which it is difficult to recover data, these costs represent only a token number of the rheumatic disease sufferers in Maine.

One of the main reasons for the major expense of arthritis treatment is the fact that people do not receive the necessary medical attention needed in the early stages of the disease. This is a result of ignorance on the part of all parties concerned. One of the duties of the Task Force shall be to advance educational activities for patients, professional and allied health professional personnel, and the public to alert the people of Maine to the early indications of arthritis and related diseases. There is a general lack of knowledge among physicians and surgeons treating arthritics about the existence, functions, and capacities of community health agencies and facilities. Physicians appear to be reluctant to refer their arthritic patients to rheumatologists. With this, rheumatologists, orthopedists, and physical therapists are not being utilized to the fullest potential.

NOTE: L.D. 1722 is pending and Mr. Blodgett intends to reintroduce the Bill in the special session of the Maine Legislature in January 1976.

D-R-A-F-T

107th MAINE LEGISLATURE  
REGULAR SESSION  
JANUARY 1975

AN ACT Creating the Maine Arthritis Task Force

Be it enacted by the People of the State of Maine, as follows:

Sec.        MRSA, Chapter        , is enacted to read:

CHAPTER  
ARTHRITIS  
SUBCHAPTER I  
GENERAL PROVISIONS

§    Short Title: This Act may be cited as the "Maine Arthritis Prevention, Treatment, Education and Rehabilitation Act of 1975."

For the purposes of this chapter, unless the content otherwise indicates, the following words shall have the following meanings.

1. Secretary. "Secretary" means the Maine State Secretary for the Arthritis Task Force.

2. Commissioner. "Commissioner" means the Commissioner of the Department of Health and Welfare or his successors.

3. Task Force. "Task Force" means the Maine Arthritis and Rheumatologic Force.

4. Department. "Department" means the Maine Department of Health and Welfare.

5. Executive Director. "Executive Director" means the Executive Director of the Maine Chapter of The Arthritis Foundation.

6. Arthritis. "Arthritis" means those disease entities described by Hollander. Rheumatologic may be used by lay persons interchangeably with arthritis.

§    State agencies to cooperate State agencies shall cooperate fully with the Task Force in carrying out this chapter. The Task Force is authorized to request such personnel, financial assistance, facilities



and data as are reasonably required to assist the Task Force Secretary to fulfill its powers and duty.

State agencies proposing to develop, establish, conduct or administer programs or to assist programs relating to this chapter shall, prior to carrying out such actions, consult with the Task Force. Each agency of State Government shall advise the Arthritis Task Force of its activities relating to this chapter.

Each state agency, in the implementation of its activities relating to this chapter, shall keep the Task Force Secretary informed of its status.

## SUBCHAPTER II

### § Office

The Task Force operations shall be administered by a Secretary who shall be appointed by the Task Force, after consultation with the Commissioner. The Secretary shall serve in the unclassified service. The Secretary shall serve at the pleasure of the consultation with the Commissioner. Any vacancy shall be filled by appointment as above.

The Secretary shall serve on a full-time basis and must be a person qualified by training and experience to carry out the type of responsibilities described in section .

The Secretary shall possess full authority and responsibility for administering all the powers and duties provided in section , with the advice of the Task Force pursuant to section . The Secretary shall assume and discharge all responsibilities vested in the office.

### § Powers and Duties

The Secretary shall establish in accordance with the purposes and intent of this chapter, with the advice of the Task Force and subject to the direction of the Task Force, the overall planning, policy, objectives and priorities for all functions and activities relating to rheumatologic health, which are conducted by or supported by the State of Maine. It is the purpose and intent of this chapter that the Task Force shall have the objectives to improve the physical well-being in Maine residents to a minimal and acceptable level; and to improve and expand rheumatological health services in Maine. The Task Force shall serve as the state's primary administrative, coordinating and planning unit for carrying out the provisions of this chapter. In order to achieve the above, the Task Force shall have the power and duty to carry out, but not be limited to, the following:

1. Ongoing review of all possible sources of funding, public and private, for improving health and development of proposals to secure these funds when appropriate.

2. Provide technical assistance and consultation to federal, state, county and municipal programs concerned with arthritis.

3. Provide technical assistance and consultation to schools and to the Department of Education and Cultural Resources for the purposes of into Maine schools health education programs.

4. Conduct studies and develop primary data for the purposes of documenting specific arthritis problems in the state.

5. Provide consultation and program information to the health profession, health professional education institutions and volunteer agencies.

6. Conduct annual reviews of the statutes and guidelines governing use of physicians and other apropos personnel and make recommendations to the legislature for changes which would benefit the public's health.

7. Administer in accordance with the interest and objectives of this chapter or within any limitations which may apply from the sources of such funds, any funds from any source for the benefit of Maine's residents in need of rheumatological services. The Executive Director shall have the power to receive for the office all funds granted by any private, federal, state, county, local or other source and the Executive Director shall use such funds to carry out the provisions and purposes of this chapter.

8. Prepare on or before January 10, 1976, and thereafter annually, a detailed report, that shall be submitted by the Commissioner. Such report shall include a statewide plan and describe the implementation of the Office. Such report shall be submitted to the Governor in accordance with Title 5 sections 43, 44, 45, and 46 and to the Legislature.

9. Carry out any other activities designed to reduce rheumatologic disease in the state.

### SUBCHAPTER III

#### MAINE ARTHRITIS TASK FORCE

##### § Task Force

The Director of the Arthritis Foundation with the advice of the Board of Trustees, shall, within sixty days of the date of the enactment of this section, establish a Maine Task Force on Arthritis and Related Musculoskeletal Diseases (hereinafter in this section referred to as the "Task Force.")

§ Membership

The Task Force shall be composed of seven members as follows:

1. Three members appointed by the Secretary of Health, Education, and Welfare from scientists or physicians who are not in the employment of the State or Federal Government, who represent the various specialties and disciplines involving arthritis and related musculoskeletal disease, and of whom at least two are practicing clinical rheumatologists and at least one is an orthopaedic surgeon.

2. Two members appointed by the Secretary of Health, Education, and Welfare from the general public. The members appointed under this paragraph shall be arthritis sufferers.

3. The Chairman of the Board of Trustees of The Arthritis Foundation, Maine Chapter, or his designee:

4. The Chief Medical Director of the Veterans' Administration, at Togus, or his designee.

The members of the Task Force shall select a chairman from among their own number.

Members shall be appointed for a term of three years, except those of the members first approved by the Commissioner, three shall be appointed for a term of two years, and three shall be appointed for a term of one year, as designated by the Commissioner at the time of appointment: except that any member appointed to fill a vacancy occurring prior to the expiration of the term for which his predecessor was appointed shall be appointed only for the remainder of such term. Any vacancy on the task force shall not affect its powers, but shall be filled in the same manner by which the original appointment was made.

Members shall be eligible for reappointment for not more than one full consecutive term and may serve after the expiration of their term until their successors have been appointed, qualified and taken office; except that members initially appointed for a one-year term may be reappointed to one full three-year term.

1. Develop a comprehensive, statewide plan--in cooperation with other statewide health planning organizations when deemed appropriate:

a. to expand and coordinate the research, treatment, and control effort, against arthritis and related musculoskeletal diseases;

b. to advance educational activities for patients, professional and allied health personnel, and the public which will alert the citizens of the State of Maine to the early indications of arthritis and related musculoskeletal diseases; and



c. to emphasize the significance of early detection and proper control of these diseases and of the complications which may evolve from them.

The plan shall be reviewed annually.

2. To recognize and support:

a. a center for arthritis prevention, research, screening, early detection, training, treatment, and rehabilitation programs, assess a need for new facilities; and

b. a program to develop new and improved statewide methods of arthritis screening and early detection;

c. establishment of a central arthritis screening and early detection data bank at the Maine Medical Center.

§ Foundation to Cooperate

The Task Force may require the services of the Executive Director of the Arthritis Foundation, Maine Chapter, and such additional personnel as it determines are necessary for the performance of the Task Force's functions.

An official employee, consultant or any other individual employed, retained or otherwise compensated by or representative of the Executive Branch of the Government of the State of Maine shall not be a member of the task force; but shall assist the task force if so requested.

Members of the Task Force who are officers or employees of the State shall serve as members of the Task Force without compensation in addition to that received in their regular public employment.

All members of the Task Force shall be entitled to reimbursement for travel, subsistence, and other necessary expenses incurred by them in the performance of their duties as members of the Task Force.

The Task Force shall review a survey of all State and local health programs and rehabilitative activities relating to arthritis and related diseases and assess the adequacy, technical soundness, and coordination of such programs and activities. All State departments and agencies administering health programs and activities relating to arthritis and related diseases shall provide such cooperation and assistance relating to such programs and activities as is reasonably necessary for the Task Force to make such survey and assessment.

The Task Force shall monitor formulation of one, three, and five year plans to combat arthritis and related musculoskeletal diseases with specific recommendations for the utilization and organization of State resources for that purpose. Such plans shall be based on a comprehensive survey investigating the magnitude of arthritis and related musculoskeletal diseases, their epidemiology, their economic and social consequences, and an evaluation of available scientific information and

the resources capable of dealing with the problem. The plans shall include at least the following:

1. A plan for a coordinated research program encompassed but not to be limited to programs of the Maine Medical Center Rheumatic Disease Laboratory, the University of Maine, Comprehensive Health Planning, Regional Medical Program, any or all divisions of the Department of Health and Welfare, any or all Federal, State, or private research projects being conducted within or without the State of Maine. This coordinated research program will provide plans for:

a. investigation into the epidemiology, etiology, and prevention and control of arthritis and related musculoskeletal diseases, including investigation into the social, environmental, behavioral, nutritional, biological, and genetic determinants and influences involved in the epidemiology etiology, prevention, and control of these diseases;

b. studies and research into the basic biological processes and mechanisms involved in the underlying normal and abnormal phenomena associated with arthritis;

c. research into the development, trial, and evaluation of techniques, used in, and approaches to, the diagnosis, early detection, treatment, prevention, and control of arthritis and related musculoskeletal diseases;

d. programs to evaluate the current resources for the rehabilitation of the arthritis patient and establish criteria for the potential for rehabilitation of the patient;

e. the coordination of a common descriptive vocabulary with a national syllabary in basic and clinical research and a standardized clinical patient data-card for arthritis and related musculoskeletal diseases for the purpose of standardizing collection, storage, and retrieval of research and treatment data to facilitate collaborative and comparative studies of large patient populations;

f. to partially support a system for the collection, analysis, and dissemination of all data useful in the screening, prevention, diagnosis, and treatment of arthritis and related musculoskeletal diseases, including the partial financial support of a State data storage bank (accessible and amenable to the existing data systems) on arthritis research, screening, diagnosis, prevention, control, and treatment to collect, catalog, store, and disseminate information as to the practical application of research and other activities pertaining to arthritis and related musculoskeletal diseases;

g. a program for the acceleration of statewide efforts for national cooperation in and exchange of knowledge on all aspects of research, screening, early detection, diagnosis, treatment, prevention, and control of arthritis and related musculoskeletal diseases for the next five years.

2. proposed State, and local programs for:

a. the education and training of scientists, clinicians, surgeons, including orthopaedic surgeons, and other health and allied health professionals and educators in the fields and specialties requisite to the conduct of programs regarding arthritis and related musculoskeletal and other related diseases.

The Secretary shall attend all meetings of the Task Force, other appropriate meetings and hearings.

The Task Force shall elect the chairperson and such other officers from its members as it deems appropriate.

§ 2098 Administrative Authority

The Task Force shall meet at the call of the chairperson or at the call of one-half of the members appointed and currently holding office. The Task Force shall meet at least once every month. The Secretary shall keep minutes of all meetings, including a list of people in attendance.

The Arthritis Foundation, to the extent feasible and reasonable, shall make available to the Task Force such staff, facilities, equipment, supplies, information and other assistance as it may reasonably require to carry out its activities.

Any reasonable and proper expenses of the Task Force shall be borne out of currently available state or federal funds. Each member of the Task Force shall serve without compensation but may be reimbursed on the same basis as employees of the state departments for the actual travel and other necessary expenses incurred in the performance of duties. The Task Force is authorized to appoint subcommittees.

A majority of the Task Force members shall constitute a quorum for the purpose of conducting the business of the Task Force and exercising all the powers of the Task Force. A vote of the majority of the members present shall be sufficient for all actions of the Task Force.

§ 2099 Powers and Duties

The Task Force shall have, regarding arthritis and related musculoskeletal diseases, the power and duty to:

1. Advise, consult and assist the Executive and Legislative Branches of the State Government, on activities of State Government related to arthritis. The Task Force shall be solely advisory in nature. The task force may make recommendations regarding any function intended to improve the quality of such physical health.

2. Serve as an advocate on behalf of arthritis health, promoting and assisting activities designed to meet at the state and community levels the problems of such individuals. The Task Force shall serve as an ombudsman on behalf of individual citizens as a class in matters relating to arthritis problems under the jurisdiction of State Government.



3. Assist the department in reviewing and evaluating state and federal policies regarding arthritis health programs and other activities affecting people, conducted or assisted by any state department or agencies.

4. Provide public forums, including the conduct of public hearings, sponsorship of conferences, workshops, and other such meetings, to obtain information about, discuss and publicize the needs of and solutions to arthritis health problems.

§ 2. Appropriation. There is appropriated from the General Fund to the sum of \$10,000 for the fiscal year ending June 30, 1977, to carry out the purposes of this act. The breakdown shall be as follows:

Department of Health and welfare	1975-76	1976-77
Personal Services (1)	7,500	7,872
All Other	2,500	2,125.

#### STATEMENT OF FACTS

(1) Arthritis and related musculoskeletal diseases constitutes major health problems in the United States that directly affect more than twenty million Americans of all ages at a cost in medical expenses of approximately \$2,500,000,000 a year. To more than 68,000 Maine arthritis sufferers this means a cost of nearly \$8,500,000 annually.

(2) The complications of arthritis lead to many other serious health problems and other severe physical impairments in persons of all ages.

(3) The citizens of the State of Maine should have a full understanding of arthritis and related musculoskeletal diseases and should be encouraged to seek early diagnosis and treatment to prevent or mitigate physical disability.

(4) The attainment of advanced methods of diagnosis and treatment of arthritis and quality-trained health professionals in arthritis deserve the highest priority.

(5) There is a critical shortage of medical facilities and properly trained health professionals and allied health professionals in the State for arthritis research, prevention, treatment, care, and rehabilitation programs.

Boston, Massachusetts

October 15, 1975

BARBARA ROTHSTEIN  
New York, New York

I would love to have time to explore the issues that arose at the "National Lupus" meeting in Boston; however, it all seems so involved it would be impossible.

We in New York have so many feelings--I personally am opposed to National as we are now at this moment in time. This is the extreme opposite position I held before the meeting.

Our MAB discussed the money necessary to meet across country and solicit grant application. We realize a national need of 1/2 to 1 million to function, hire people, etc. Most people were very naive--and thought \$1.50 per person would cover all expenses. Also, all existing chapters did not want to contribute a percentage of their moneys to fund national matters, i.e., research, public relations work, etc. Therefore, I must say New York has nothing to gain.

We need national research, but as we are presently structured, we cannot undertake a national MAB.

We need to merge with other strong groups--D.C., Connecticut, Pennsylvania.. They are near enough to provide common services, and yet not deplete our money.

Lupus is unique, we do not have a group of strong, intelligent, sophisticated, rich and non-lupus stricken people to work.

By the way, your representative never introduced himself to us--never spoke. In fact, I think he did make a brief appearance and that was that. I was very upset. His position and ideas would have been helpful. We searched for him, but to no avail.

We really need more HEW Fact Sheets and hope by now the Lupus Foundation is mentioned. Please send us as many as you can spare--right now we want to mail out over 1,000 and have so few left.

MAXINE VARDACK  
Buzzards Bay, Massachusetts

October 12, 1975

When anyone asks me to talk about arthritis I feel like a picture I saw in the paper from East Africa of one of the recent heart transplant patients coming out of a grocery store with his wife. When the reporters rushed up to ask him questions, he just took a big brown grocery bag and put it over his head.

Arthritis is one of the most heartbreaking, agonizing, dreadful diseases, and should be in a class with cancer--only you don't die--you just wish that you could. But of all the horrible diseases it is the most abused and misunderstood by the general public. Research money should be the primary target to find the cause and cure. These are a few of the reasons why we need to re-educate the public.

First of all, rheumatoid arthritis and lupus are the only critical ones out of hundreds of less serious forms. People send me clippings, copper bracelets, and other home remedies and always show me a little finger to identify with me that they, too, have arthritis. But unless it is rheumatoid I know it's another ball game.

The medium is constantly bombarding us with advertisements of aspirin for simple arthritis. A woman standing in the window takes an eight-hour release aspirin and with a big smile goes to work cleaning her house like hell. Another advertisement shows a young woman popping in some aspirin, then she puts on her raincoat, grabs her children, puts them in the station wagon and drives them to school in the pouring rain. Manufacturers must enjoy selling hundreds of tons of it. I'm only saying why not pull rheumatoid arthritis out of that big world of misunderstanding. Call it by another name or something, you name it.

The experiences one meets outside of a specialized hospital like Robert B. Brigham are unreal. A lot of doctors are very comfortable with the way things are. Recently I was in California and felt very miserable so I thought I might talk to a doctor and try to get the new drug motrin which wasn't available at the time on the East Coast. He said, "I don't treat arthritis, but I will be glad to give you a prescription for motrin." Later when I ran out of motrin in Texas I went to another doctor and told him I had rheumatoid arthritis and that I was feeling terrible. I said my sedimentation rate must be awfully high. He said, "What's that got to do with rheumatoid arthritis?" I said, "Nothing as far as we both know. I really came to get another prescription for motrin." He said, "Does it help?" And I said, "No, it is no miracle, only I can tolerate being off of aspirin which over the years was having side effects."

Another mask for rheumatoid arthritis is all the new total joint replacements. I am fully aware that probably the latest advances in surgery have been in joint surgery. Some surgeons are so hepped up over these new joint replacements they think they are putting them in racing cars! Now I'm not discrediting these advancements, a great achievement in orthopedic surgery. These replacements for football players, auto accident victims, fortunate people with simple arthritis will go home, heal up fine, and thank medical science. However the poor rheumatoid arthritic patient with that big sediment rate (which makes no difference!) must go home sick as a dog with a systematic painful disease running through his tired body. He crutches around, putting extra weight on the other knee. In six months it swells, becomes so painful he must go back for another replacement. Next go the hips, until by and by all the cartilage in the joints is gone and joints must be replaced. The general public thinks that once you have had a joint replaced you're cured and like everyone else.

The only time I feel like putting a bag over my head is when I'm passing by the children's ward at Robert B. Brigham and I see the little children with rheumatoid arthritis who do not realize the life of suffering ahead of them. Most of them will be taken out of life's swim completely.



Let's work our way through the masks and booby traps, always keeping in mind the main target--RESEARCH.

I'd like to see money collected for research of those critical diseases such as cancer, multiple sclerosis, muscular dystrophy, and rheumatoid arthritis, housed in the same research building; centers in different parts of the country instead of money sent to individual universities. Money could be saved because of possible overlapping. In the search for a cancer cure we might find one of the other cures in the shuffle.

I'd like to see more specialized hospitals in different parts of the country. When I get away from Robert B. Brigham I almost have the feeling that it is my lifeline. As you well know, even orthopedic surgery is different for an arthritic.

Let's not put a bag over our heads. Let's cut holes big enough for our eyes so we can see things as they really are!

SANDRA J. COYLE  
New Bedford, Massachusetts

September 39, 1975

I am 32 years old and have had J.R.A. since the age of 7, and if I was to combine my feelings into one statement it would be that the average person is totally unaware of the seriousness of R.A., and has no comprehension of the difficulties involved in the everyday activities of an arthritic.

To explain in detail my problems as an arthritic would take many pages so I will briefly outline my major concerns:

## I. Lack of Indépendence

### A. Transportation

- 1) I am ambulatory but cannot utilize buses, and must take taxies in an emergency.

- a. cost is prohibitive

- 2) I have others drive me in their cars

- a) Can only sit in front seat if 2-door

- b) Cannot open door if push button

### B. Money

- 1) Bureaucracy sets limits on Income

a) Fear of losing medical benefits leaves one with no incentive to work when feeling well

2) Life insurance unavailable

C. Physical Barriers

1) Stairs

2) Public Transportation

3) Recreational facilities

4) Subways

5) Public toilets

II. More Federal Funds for Research

THOMAS P. MULDOON  
New Bedford, Massachusetts

September 27, 1975

I would like to go on record in support of the Arthritis Foundation.

Having suffered for close to twenty-five years with the intense pain, swelling and fever caused by this form of arthritis, i.e., gout, I would fully support any assistance given the Arthritic Foundation.

FRANCES MULDOON  
New Bedford, Massachusetts

September 27, 1975

I would like to be numbered with those who are in support of the Arthritis Foundation.

MARY F. MULDOON  
New Bedford, Massachusetts

September 27, 1975

I would like to go on record as a supporter of the Arthritis Foundation. My husband has suffered with gout for 25 years and any research that could help others would be just great.

ELINOR C. KLASKY  
Wakefield, Massachusetts

October 3, 1975

I hope this letter does not arrive too late to be included among those who are concerned about arthritis here in the Boston area.

As a parent of a daughter who has systemic lupus erythematosus, I am well aware of the implications of a chronic disease. Adolescents have a difficult time, anyway; when coupled with a systemic, painful disease,

Boston, Massachusetts

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unknown to most, and in some cases requiring casts, crutches, and avoidance of sun -- it is hard to live with. "Coping" is helped by the support of family, friends, and excellent medical care, plus the knowledge that research is directed toward this sometimes fatal disease.

The chronic disease affects those around the patient, too -- his siblings, his parents, his peers. They also need support to cope with the effect on their own lives.

The dearth of correct information of many professionals and the public is appalling. People tend to think of arthritis as an "old age" disease. SLE was considered a fatal disease of young women. Many dictionaries and reference books have outdated material on lupus. But now statistics show 90% survival for ten years. Unfortunately, though, misinformation still occurs.

Enclosed is a most recent example--9-30-75. Well intentioned, concerned, and sincere, nevertheless, a television station and a newspaper advertisement issued erroneous and upsetting information. That this could happen in Boston, the site of major teaching hospitals dedicating some research to lupus, illustrates just how much more needs to be done.

Research--so a cure may be found. So no young person will have to go through life with the pain and the uncertainty of this disease. And support--financial (the funds of the Mass Rehabilitation Commission have been cut; therefore, they have had to cut back on financial aid), health insurance (some patients are not covered), and especially, knowledgeable support of schools, family and peers; the medical profession; and the general public. Hope, education and research must replace despair and ignorance.

It is hard to be "different," to have life's experiences go on without you. It is hard to have pain, to adhere to a goal in spite of discomfort and uncertainty. It can and is possible to have a productive, worthwhile life, but it takes courage and support.

Thank you for your interest and support. I appreciate this opportunity to express my views. I am looking forward to the hearing of the National Arthritis Commission on Wednesday, October 15, 1975.

PETER H. SCHUR, M.D.  
Boston, Massachusetts

September 26, 1975

In response to your request I would like to submit the following as a summary of remarks I would like to give before the National Arthritis Commission on Arthritis and Related Musculoskeletal Diseases which is meeting in Boston, October 15th. I would like to limit my remarks to the problem of systemic lupus erythematosus.

Systemic lupus erythematosus, SLE, is a form of arthritis affecting primarily women, particularly those in their 20's and 30's. It affects nearly half a million people in this country. In fact, it has been estimated that one in 50 women in their 20's and 30's has it. In contrast



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to most of the other types of arthritis it is usually associated with other organ system involvement including skin, blood, kidney, brain, lungs, heart, etc. Also in contrast to the other forms of arthritis it can be fatal. In fact, it is estimated to cause 5,000 deaths per year. As a physician taking care of a large number of patients with lupus, I am particularly frustrated by the lack of public, medical profession, and paramedical profession knowledge regarding this disease. Many have never heard of it, many of those who have heard of it are not aware of the newer techniques available for its diagnosis, and more important, many such individuals are not aware of the new advances in therapy. This requires a large educational undertaking.

However, as a researcher and physician, this is not good enough. One must find the cause of this entity and thereby hopefully develop the means to eradicate it. On behalf of my patients I hope that the National Arthritis Act will provide the means to find such a cause and cure in the near future and in the meantime provide better care for patients, make this care available to all patients, and make known to the public that care is available.

MRS. EDWARD T. RICHARDS  
North Providence, Rhode Island

October 1, 1975

I sincerely regret not being able to attend the National Arthritis Commission public hearing in Boston, October 15, 1975. Having just come home from the hospital it is simply impossible for me to travel and my husband must work that day. Otherwise, I would definitely be there.

My daughter has had juvenile rheumatoid arthritis in all joints for 8 years. She will be 10 years old in December.

When our R.I. Chapter of Arthritis was needed years ago for home therapy it was available and they were marvelous. I then continued and my daughter held her own.

Due to illnesses, problems, etc., she has not received daily therapy since February 1975; hence she is suffering with pain in all joints and deformity in her hands.

The United Fund has cut our chapter's home-care therapy as of this date. This is a disgrace! Visiting nurses can come in once a week.

Why can't we have home care therapists when it is an absolute necessity? You must realize the importance of a rigid every-day therapy program for the rheumatoid patients!

Why can't we have a center with trained therapists strictly for the arthritic and other rheumatic diseases? Why when Medicare covers everything else for the elderly, will it not cover home care for a senior citizen?

Why can't we have a national telethon with local stations joining in? Why must arthritis be funded by United Fund? By the time the money is channeled down, we have nothing!

If Congress can appropriate billions of dollars for wars, space flights, starving children in other lands, etc., why can't they help 20,000,000 suffering people in America?

In my estimation, arthritis is the "Forgotten Disease". People are ignorant of the fact it is not a disease of the elderly alone. It affects and can cripple thousands of children. These children are our future citizens. What then?

This letter is filled with questions. My husband and I are asking for 20,000,000 suffering people. We want answers and we want them soon.

Something must be done now! Help stop arthritis, before it stops you!

You may use my name at any hearing or meeting that is held concerning arthritis.

EDWARD J. GOETZEL, M.D.  
Boston, Massachusetts

#### ARTHRITIS RESEARCH--THE NEED FOR CENTERS

The inadequacies of the currently available medical and surgical treatment of arthritis are painfully obvious to arthritic patients as well as their families and physicians. Although there is still need for improvement in the dissemination of details of accepted modes of therapy to both physicians and patients, it is not the major goal of this decade. Our most important challenges are unraveling the causes of arthritis, developing methods to detect severe arthritis at an early stage, and discovering both truly effective medications to eradicate disease and procedures to restore function to previously damaged joints. The ultimate success of basic and clinical research is dependent upon a concentration of resources that will encourage problem solving at the highest scientific levels and allow the appropriate application of new advances to clinical trials. Today I will direct my remarks to those elements of our research efforts which have been and will be critical to improving our understanding and care of arthritis.

A research project in arthritis is usually initiated by an investigator or team of investigators who have discovered a possible causative agent or abnormal biologic process in laboratory models of inflammation or have developed a potential new drug or surgical procedure. A team effort is required to continue the development of their findings and to extend their studies to patients with arthritis. A variety of collaborators and consultants with special expertise must be available to provide insights, methodology and experience. This was true for my own studies of aberrations in the respiratory physiology of diseased joints. The work spanned three years, one at Harvard Medical School, and two at the National Institute of Health, during which time I collaborated closely

with a physician who had spent several years analyzing related problems in pulmonary physiology. We discussed our approach in detail with a large number of physiologists, biochemists, and statisticians. During a more recent study of a protein antigen in arthritic synovium which selectively attracts mononuclear white blood cells, I have worked with a biochemist at Harvard Medical School and a peptide hormone chemist at the Laboratory of Reproduction and Reproductive Biology.

In addition to intellectual and methodologic capabilities, facilities must be available to provide excellent care of in-hospital and ambulatory patients who are cooperatively engaged in research protocols. These facilities should optimally be staffed with specially trained nurses, study secretaries, and fellows-in-training. For the fellows, an exposure to properly organized research is an important part of subspecialty training which will expand their general understanding of rheumatic diseases. Such experience will also facilitate their participation in future research projects after completion of their training.

Finally, the most critical link between the investigators and the patients is a cluster of practicing rheumatologists and orthopedists who both understand and support the research and are capable of delivering first-rate comprehensive care to arthritic patients. Such physicians and surgeons can refer appropriate patients to arthritis research centers for initiation of a protocol and provide astute long-term follow-up essential to the completion of clinical studies. In view of the chronic nature of arthritis, truly significant research cannot be accomplished by single measurements or brief trials of therapy. Extended trials of drugs and surgical procedures are best carried out in cooperation with practicing specialists who have assisted in conducting similar trials during their training period.

Although a few university center hospitals are already capable of carrying out basic and applied research in arthritis, none are optimally equipped or staffed to respond to the challenge in an efficient and comprehensive manner. Our greatest need is for new programs to provide special training for not only career scientists but also practicing rheumatologists and orthopedists who wish to meaningfully expand the base of current research while providing excellent care. Such practitioners can look to the arthritis centers for their postgraduate education and for special tests and procedures for patients as well as organized involvement in meaningful research. In addition, centers could coordinate regular meetings and systematic interchanges among arthritis investigators and physicians and scientists in other disciplines who are capable of contributing to arthritis research. Further, centers would expand computer facilities devoted to arthritis research to allow recall of selected groups of patients and relevant clinical data and encourage a systematic approach in all phases of patient care.

In summary, I believe that the best hope for improved medical and surgical care of arthritis lies in a broad basic and clinical research program which is best coordinated at centers that can offer intellectual and technical expertise, organized populations of patients and training for full-time investigators and research-oriented practitioners.



ROBERT LEFFERT, M.D.  
Boston, Massachusetts

I should like to briefly address the problem of the great need for support for medical and social rehabilitation measures for sufferers of arthritis and related diseases of the musculoskeletal system. Since there are an estimated 20 million Americans affected by these diseases, the problem is one of considerable magnitude. However, since they usually do not, like cancer or heart disease, result in death of the patient, they are often relegated to a low priority in the general view. Since they constitute one of the major causes of crippling, incapacity, and suffering in a population that is getting older--rehabilitation measures are needed to lessen the sequelae of their chronic states.

The following areas will be stressed:

- (1) Education of the lay public as to the scope, application and availability of clinical facilities and services to prevent potential deformities or joint dysfunction and to treat those already present.
- (2) Coordination of physician activities in employment of physical modalities, orthotic and adaptive devices along with medical and surgical therapy in the patient with acute and chronic joint disease.
- (3) Training of nurses, physical and occupational, recreational therapists, as well as medical students and graduate physicians in the rehabilitation aspects of arthritis.
- (4) Development of scientifically sound programs for research and evaluation of those physical modalities that have traditionally been employed in treatment with the aim of eliminating ineffectual ones and developing or protecting those that are truly of value. An offshoot of this would be an intensive effort to eliminate "quackery" and to educate the public in this area.
- (5) Finally, the establishment of guidelines for and methods of employment of patients affected by arthritis and rheumatism so they are not unnecessarily or prematurely lost from the active work force of the nation.

Boston, Massachusetts

October 15, 1975

REBECCA K. LOVE  
Saco, Maine

November 26, 1975n

I regret not being able to attend the Arthritis Commission hearing in Boston; undoubtedly what I am writing about has already been suggested, but herewith what has been on my mind.

I believe one of the best things the Commission can do is to spend a large portion of what funds it may get, in educational spots on T.V., to reach people who either can't, or believe they can't, afford to go to the doctor. These spots to contain:

- (1) Information on approved, simple, home remedies and helps, i.e., hot wax for hands, knees and how to use it.
- (2) Where to find mechanical helps at reasonable prices or how to make them, i.e. -- long tongs, can holders (for use by one-armed people.)
- (3) Simple instructions for exercises to keep joints moving but never straining.
- (4) In short, all general information (that people who do get to their arthritic doctor receive).
- (5) Finally, of course, to be offered at the close of each spot, would be a pamphlet containing the above information, and listing other sources of information on the above.

NONA HAMMER  
New York, N.Y.

November 11, 1975n

We the undersigned are indeed very fortunate to be members of a very special out-patient group at Columbia Presbyterian Hospital in New York City.

We meet weekly for two hours. The first hour is devoted to discussion of individual or common problems related to arthritis and rheumatoid diseases. We also use the first hour to plan holiday and other parties. For many of us it is a highlight of our week. We encourage our members to cook, to make things with their hands, to shop for each other and to be helpful with family problems. Our second hour is devoted to exercise, movement to music and games.

Our members have benefited physically and emotionally from this group activity. At times they begin to laugh and move in ways they never thought would be possible. The group support as well as that of the social worker and physiotherapists who work with each member individually is very unique. The social worker and physiotherapists really care about us and because of these factors many members are adjusting to their handicap.

We as a group would like to see many more groups formed in hospitals for arthritis and patient care centers such as ours.

In addition we would like to propose the idea for the creation of a rehabilitation and vacation center to be located in a warm suitable climate, where patients who have arthritis and other related diseases could go for an annual period of time. Patients need a break from their difficult routine and their constant stress of pain. Here is an ideal setting where such relief could be found. Too often patients afflicted with arthritis, lupus, and scleroderma suffer in isolation.

There is also a great need for vocational seminars and workshops to help patients become more independent.

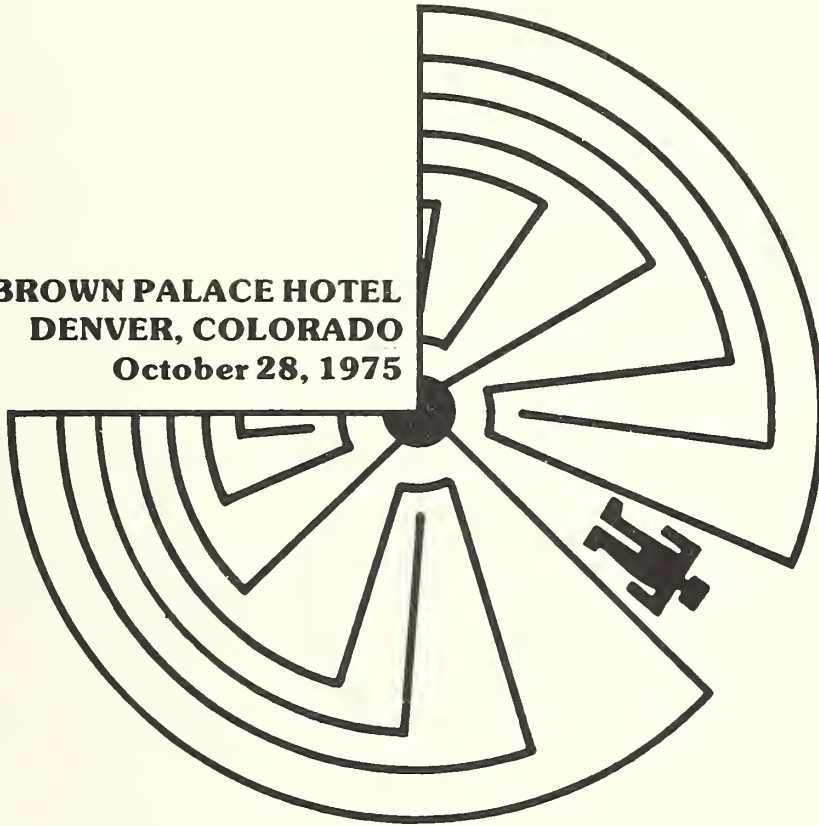
Groups such as ours can facilitate more professional and public education to increase awareness of these diseases.

We appreciate the Commission's interest in the improvement of care for patients, as well as the contribution of allied health care professionals.





**BROWN PALACE HOTEL**  
**DENVER, COLORADO**  
**October 28, 1975**







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P R O C E E D I N G S

ENGLEMAN: Now I want to discuss the appreciation of all of us to all of you who have taken such great effort to be here this morning. It is gratifying and reassures our Commission that the public hearings are of interest to the public as well as to us and that we can look forward to very valuable and constructive testimony, suggestions, and how the National Arthritis Act might be best implemented. As you know, the National Arthritis Act, which was passed by Congress in December of 1974 and signed by the President in January of 1975, authorized the use of \$50 million for research and medication and provisions programs in arthritis.

The emphasis is on authorization, it doesn't mean we have the funds. The first thing that happened was the appointment of the Commission, which was charged with the responsibility to come up with a plan, a National Arthritis Plan which would then be submitted to Congress, hopefully for funding. And the efforts of the Commission in these last few months and in the next few months are focused on the construction of a National Arthritis Plan which is feasible and which will be most effective for most people. What we are interested in now are your suggestions on how such a plan should evolve, where you think the emphasis should rest. What can we do, not only to help you locally, but what can we do to create a much needed and long overdue National Arthritis Plan?

Now before we start, I am going to ask those of us, those members of the Commission who are here, to identify themselves. My name is Engleman, Ephraim Engleman. I am a practicing rheumatologist and a member of the staff of the State University of California in San Francisco.

SHIELDS: I am Marlin Shields. I am a physical therapist from Salt Lake City, Utah, and I am representing the allied health professionals on the Commission.

GAY: Dr. William Gay, Associate Director of the National Institute of Allergy and Infectious Diseases.

POLLEY: I am Dr. Howard Polley; I am a rheumatologist in Rochester, Minnesota.

JENERICK: I am Dr. Howard Jenerick, representing the National Institute of General Medical Sciences \_\_\_\_.

BATCHELOR: Dr. Bill Batchelor. I am from the National Institute of Arthritis, Metabolism and Digestive Diseases. I am currently serving as the Executive Secretary of the Arthritis Commission.

ENGLEMAN: I will ask all persons who are appearing before the Commission to clearly state their full name, title, organizational affiliation, if any. We urge you to submit and make available a written testimony, as well as oral. The written testimony will be incorporated into a volume which will accompany our report to Congress.

We will now call on our first witness, Mrs. Elva Dulan. Mrs. Dulan?

By the way, I failed to mention that because of the number of witnesses and the very serious time constraint, we only have four hours, we must restrict your oral testimony to no more than four minutes. And this will permit some that have questions and answers from the members of the Commission.

TESTIMONY OF  
ELVA J. DULAN, R.N.  
DENVER, COLORADO

DULAN: Mr. Chairman and members of the National Commission on Arthritis and Musculoskeletal Diseases:

My name is Elva Dulan, employed as Assistant Director for Community Health Nursing at the University of Colorado Medical Center for eleven years, and then retired for disability one year ago. I am here today as a nurse and also a patient who has been a victim of rheumatoid arthritis for ten years.

It has been an insidious, destructive, crippling disease for me. Nine years ago the disease started with minor pain and swelling in the fingers, and then progressing each year or two to more extensive joint involvement. I think I was optimistic, at first, about a remission at any time along the continuum, but with medications, including some investigational drugs and treatments, the illness continued to progress. With the very best of medical care available, the disease progressed until there was complete deterioration of both knee joints two years ago. I was unable to walk and finally had to use a wheelchair while carrying out my job at the hospital.

Surgery on my knees was suggested a year before I agreed to have it done. There was no medication or treatment that would help the loss of the cartilage and bone destruction in the joints. I agreed to have surgery, but felt this was the end of my active life. I had a vision of a completely helpless cripple and a feeling of great depression. Having lost my husband through death a few months prior to surgery, I was left without physical, mental, or emotional support.

My surgery was performed a year and a half ago. A total knee joint replacement was performed on the left knee and, two months later, the same operation was done on the right knee. My hospitalization was ten days each time. I made an excellent recovery according to the physicians. I was on crutches, it seemed forever, but gradually began to stand, walk, and bend the new knees without pain. I have now graduated to the cane that I only need when walking long distances, ascending or descending steps. I am grateful and most appreciative to the doctors and medical personnel. I still have involvement in my shoulders, ankles, and wrists. Future surgery has been suggested for my wrists because there is progressive involvement.

My concern now is what kind of follow-up care will be in the future for me and other victims who may have problems developing from the new procedures which are still in the early experimental stages. I have



observed patients and also experienced the emotional trauma and mental anguish that go along with the crippling and deformity, plus the ego deflation and blow to the self-esteem. The knowledge that there is so little relief to look forward to makes the disease the most horrible of chronic illnesses.

As a professional nurse and a victim of arthritis, I appeal to the Commission to urge appropriate funding for more medical and paramedical personnel, more research, education, and patient care programs for diagnoses, treatment, and follow-up. The team approach is essential to help the millions of sufferers for whom there is no absolute cure at this time.

ENGLEMAN: Thank you Mrs. Dulan. Any questions from members of the Commission?

Mrs. Dulan, you have asked for a lot of things, research, education, patient care, and so forth, you have sort of covered the waterfront. Obviously we are going to have to have priorities. Our resources are going to be limited, we do not unlimited funding. Do you have any specific priority order? Do you have any feeling for what you would like to see supported in order of priority?

DULAN: Well I think research is very important, and it seems to me that the progress that has been made in surgery is also very important.

[Recording interrupted.]

ENGLEMAN: I see we have a new member of the Commission. I mean, he is not a new member but he is newly arrived. Would you introduce yourself please?

WHEDON: I am Dr. Don Whedon, I am the Director of the National Institute of Arthritis, Metabolic and Digestive Diseases, part of the National Institutes of Health, and a professor.

[Recording interrupted.]

TESTIMONY OF  
BARBARA SCHLEICH  
PATIENT  
HAYS, KANSAS

SCHLEICH: Mr. Chairman and members of the Arthritis Commission:

My name is Barbara Schleich, and I live at 301 W. 32nd St. in Hays, Kansas. I am 45 years old and have had arthritis since I was a year old. My grandmother, father, and two sisters have also had the disease, so I feel I know a bit about it, at least from the patients' standpoint.

I have been asked to tell a little of what it is like to have arthritis. For me, besides the almost total dependence on others and the isolation, which I think bothers most severely handicapped, what really

bugs me about the disease itself is not so much the pain (although I am sick of all those commercials on "arthritis" minor aches and pains"), but its progressive nature. Just when you think you have your life arranged so that you can live fairly comfortably and maybe even plan ahead, you find you can no longer reach, lift, or do at all, something that could formerly be done easily. Sometimes this change is so gradual you don't realize it is happening, and sometimes it comes quickly after a flair up. In any case, you can seldom regain what you have lost, and you are left with the choice of either giving it up, or, if possible, finding an alternate way of getting it done. After so many years of losing motion and increasing weakness, the future starts to look pretty grim.

I would like to urge that more money be spent on research for a cure for arthritis. My sister, a UFO buff, once said only half jokingly, that if she ever met one of the little green men, her first question to him would be, "Have you a cure for arthritis?" With my luck, they wouldn't have the answer either, but this shows just how desperate you can get for help.

Then, as I have had the benefit of quite a bit of corrective surgery, cups in both hips, my right elbow and knee made movable, and, as you can see, they are working on me again, I would hope you will continue research along this line. I have joints in trouble I don't think anyone has even thought of fixing.

Now, I would like to talk a little about these new Regional Arthritis Centers and what I would like to see included in them. First, I was glad to hear these centers will be regional as through the years I have had to travel all around this country to find help. As my family and I grow older, it has become more and more difficult, and I do hope that it will not be too hard to get to these centers.

At the top of the list of what I would like to see included in these arthritis centers is, of course, good, qualified doctors, having seen some who seemed to know very little about the disease. Then, a good Physical Therapy Department is a must with arthritis. Next, what I consider one of the most important departments, Functional Therapy, or Occupational Therapy, as it is known in most hospitals. Through training and the creating and fitting of adaptive equipment, this department can make life more livable for the severely handicapped patient after the doctors have done all they can do.

I would also like to suggest, either in connection with OT, or on its own, some sort of repair or maintenance department. Over the years I have accumulated a lot of special equipment, and one of my biggest headaches has been trying to keep it repaired. As an example, I might cite this chair, which I more or less live in. It is now over 12 years old and slowly falling apart. In the small town where I was born, I was finally able to locate a "jack of all trades" who, if he could not find a spare part, could improvise something that would work. Since moving to Hays, I have had to find someone to fix the wiring and switches, someone to find new tires and put them on, someone to get and put on new drive belts, and an upholsterer to stitch up a new back. What a relief to find Dr. Smyth's Arthritis Pavilion, where, while being treated, I could also get missing

spokes replaced, a new brake extension, and many other things done that needed doing. How great it would be if all these centers could carry, or have access to, spare parts, with someone to install them (very important) and even alter them, when necessary, to fit the patient. Most big hospitals do have good physical therapy departments, but I have found few places where equipment used every day by the arthritic can be repaired, let alone fitting him with new gear.

In addition, I would think some type of counseling for those just learning they have arthritis and some help with home care, a good thing.

My last recommendation is for Federal aid to help patients buy equipment. In many cases this might enable the arthritic to hold a job, either at home or help him to get out to one, or just achieve a little more independence. I was unable to afford this chair until I was over 30. Over the years I have managed to buy quite a few things, but it took many years of saving, and I know many are not as fortunate as I. Right now I would like to get a van with an automatic lift, so I could take this big chair when I go out. As it is now, the act of loading and unloading me and my little folding chair, plus the fact that I then must be pushed upon reaching my destination, cuts down greatly on my mobility. Yet with higher prices, I doubt if I can ever afford one. What a blessing it would be if the government, in some way, could help with these large expenditures for special equipment.

Thank you.

ENGLEMAN: Thank you very much Mrs. Schleich.

SCHLEICH: This is a picture that I have painted and brought to one of my doctors.

ENGLEMAN: You painted this yourself? Would you mind showing it to the audience please? I wonder if there are any questions from members of the Commission? Mrs. Schleich, do you live in Denver?

SCHLEICH: No, I live in Kansas. Hays, Kansas.

ENGLEMAN: How far is that from Denver?

SCHLEICH: It is a seven-hour drive, I don't know the mileage.

ENGLEMAN: And how often do you have to come to Denver?

SCHLEICH: This has been my second trip here.

ENGLEMAN: I see, most of your care has been given in Kansas.

SCHLEICH: Well, most of my surgery has been at the Mayo clinic.

ENGLEMAN: I see.

SCHLEICH: Many years ago.



ENGLEMAN: That is a little institution that we have heard of in the past. I knew you would find that out.

SCHLEICH: Well, at first we had Houdini try to work on me.

ENGLEMAN: I see. Yes.

POLLEY: I would like to say that I think we are all impressed by Mrs. Schleich's inner resources. She is an inspiration to everybody on the Commission as well as the rest of you, but even beyond that, I think she represents the fact that the public research communities and all the rest of us can no longer afford to have people like her around. We have got to do better.

ENGLEMAN: I think we would all have something similar to say, would agree with Dr. Polley. Any other comments or questions? Yes.

VOICE: I was impressed at seeing that painting that you had done and, as I have seen a lot of handicapped people in my day, I would possibly at this point mainly not even consider you handicapped in terms of the fact that it is apparent that you have not been spending your life focusing on what you didn't have; you have obviously spent your life focusing on what you had left. And I think that is a great attitude and probably contributed much to your success and you are to be commended.

SCHLEICH: Thank you.

ENGLEMAN: I think the audience also ought to know that she gave that painting to Charlie Smith.

We will now proceed to hear from Mrs. McGillis.

TESTIMONY OF  
JOANNE S. MCGILLIS  
PATIENT  
SALT LAKE CITY, UTAH

MCGILLIS: Mr. Chairman and members of the Arthritis Commission:

I am Joanne S. McGillis, 43 years old, residing in Salt Lake City, Utah. I am married and the mother of a married daughter and two sons. Additionally, my father, stepmother, younger brother and his family, comprise my loving, supportive family. I enjoyed an active healthy adolescence, was an honor student and engaged in a variety of sports. I have assumed positions of leadership in community organizations and philanthropic causes, and I am currently serving as a board member of the Utah Arthritis Foundation, in the capacity of public relations chairman.

I have been asked to appear here today because my story is somewhat unique. I do not display the overt appearance of one who is chronically ill, yet I suffer from a form of arthritis, termed fibrositis (or sometimes called muscular rheumatism) - a name given to a combination of symptoms of aches, pains, and stiffness in various parts of the body,

accompanied by weight loss, weakness, fatigue, and muscular spasm. Clinically it is not considered serious and is not terminal, but management and treatment are difficult and prolonged; for me and my family it is extremely serious! It has drastically changed my life style: it has altered my moods and disposition: it has affected my relationships: it has produced a constant atmosphere of anxiety and apprehension.

I have had to deal with my fear of pain (which I had always associated with death) and the lonely experience of pain itself. I have known depression and frustration, as the result of medication administered on a trial and error basis, and/or the symptoms of fatigue - also the inability to cope with routine household management and family affairs. I have been angry at having to submit to my limited capabilities - asking my family and friends to accept a little less, help a little more, and understand a great deal. I have even felt resentment watching them engage in active sports, since the transition from participant to spectator was not easy for me. It has taken three long years for me to accept the inevitable - there is no magic cure, no miracle drug, and only the possibility of periods of remission - which necessitates a substitution of quality rather than quantity in my life and a prescribed regimented routine of rest, medication, therapeutic exercise, self-control, and patience. The good days and painless hours have become extremely precious.

A number of factors compound the problems of a non-articular arthritic. The very fact that there are no scars, no visible evidence of physical damage, can in itself be devastating and emotionally crippling. I can sense the disbelief when I tell acquaintances that I cannot properly function until nine or ten a.m. - that I must rest each day and retire at a reasonable hour. I have heard blatant gossip that I am enjoying an exquisite form of self-torture and basking in my hypochondria. I have had nurses tell me that I don't look like I am in pain. I have been advised by interns and residents that I suffer from "middle-age phobia" and "children leaving the nest syndrome." Certain ethnic groups respond more dramatically to pain, so a neurologist informed me. It was even suggested to me by a psychiatrist, specializing in self-hypnosis for relief of pain, that if I gave up smoking and bought a new mink coat my illness would disappear.

I cannot buy the theory that arthritis is psychosomatic in origin; however, I am convinced that emotional upsets are damaging to the existing condition. I can forgive the individuals who are victims of misleading and/or no information. I find it difficult to excuse professional personnel whose callous indifference indicates lack of understanding and education concerning the total aspect of arthritis and its manifestations in many different forms.

Treatment of a chronic disease for which there is no known cause or cure is a frustration for both patient and physician. It can be likened to irrigating the Sahara Desert with a thimble of water. Obviously, a concentrated research program deserves top priority. Meanwhile, for the millions of arthritics suffering today and those who will be affected tomorrow, I see an urgent need for the following:

- (1) Community education designed to increase public awareness and understanding of arthritis; a concerted effort to combat the harmful effects of advertising, which promises instant relief from the minor aches and pains of arthritis, by a more direct and truthful approach - arthritis may not be a killer but it can be a living death.
- (2) Compulsory education and training programs to include all ramifications of the disease for the medical and paraprofessional groups whose skills are necessary in treating the disease.
- (3) Instruction and counseling classes to include the patient's family, in order to clarify their role in management and coping with the emotional trauma of a chronic disease. Arthritis is a family affair.
- (4) Recruitment and training of volunteers to assist with seminars, films, and all forms of mass media.
- (5) Establishment of arthritis clinics: providing instructions, recreation, swim classes, counseling, referrals, and therapy.
- (6) An increase in the number of qualified specialists to relieve the overburdened, all too few rheumatologists - thereby allowing sufficient time during office visits for physician and patient to re-evaluate psychological factors and clinical treatment.

I realize that solutions for the problems of arthritis create a gigantic challenge. However, if some effort is not made to drastically implement means of education and communication, the public will not be sympathetic to our cries for help and our pleas for money.

DIAGNOSIS:        HOSPITALIZATION        COMPLETE WORK-UP, INCLUDING BIOPSY  
PROCESS OF ELIMINATION BY RULING  
OUT EXISTENCE OF ALTERNATIVES

MEDICATION:     DAILY DOSAGE:        4 mg Medrol  
6 500 mg Motrin  
  
Darvocet-N = relieve pain  
Rela = acute muscle spasm  
Dalmane = sleep

ENGLEMAN: Thank you, Mrs. McGillis. Any questions, comments? Then we should go on to hear from Miss Neal, Miss Geraldine Neal.



TESTIMONY OF  
GERALDINE NEAL  
PATIENT  
DENVER, COLORADO

NEAL: My name is Geraldine Neal, and I have juvenile rheumatoid arthritis. It started when I was 17, and I barely got to graduate. When I found out that I had the disease I did not go to a doctor for two years, and when I finally went, the disease had begun to get worse.

I went to Colorado General Hospital, and they tried to convince me to have an operation when the disease was worse, and I had turned them down for two years. And then finally the disease got so bad that I had to have the operations. My first operations--my first two operations--were in March, I had both my hands done, I had my knee done, my left knee done in April, my right knee done in July. Operations have relieved the pains in those joints that have been operated on and I am thankful for that.

I would like to say, too, that getting arthritis at a young age is very trying mentally. I had my life planned out and things to do, but when I was struck down with this disease not only did it destroy me physically but also mentally. I thought of many ways of committing suicide and killing myself because I thought life was not worth living with the pain and the deformity. My parents, my family, didn't understand what I was going through, which was hard on me, too.

I would like to say that for me, not only have I needed help physically but mentally. That is the worst stage I have gone through with this disease, just getting my life back together. I am 24 years old, I will be 25 next month. I just hope that other young kids won't be as foolish as I was, if they feel something is wrong with their body, especially in their joints, that they will go to the doctor as soon as possible. I wish often that I had.

And I am just thankful that there are people who care, especially at Colorado General and General Rose. If it weren't for them, I might be dead today. Thank you.

ENGLEMAN: Thank you very much Geraldine. I think the audience should know that Geraldine spoke extemporaneously, without any notes, so you know that this is from her heart. Geraldine, if you had your druthers, if you could have anything that you wished, anything that we might be able to do in terms of supporting, in terms of financing, in relation to this Arthritis Act, what would be your first choice? What do you think is the thing that is most important from your point of view?

NEAL: Definitely getting physical help for the body and, secondly, most important to me also is mental help, too. That is important, because you can get, like somebody told me, physical help, but if you don't have the mental faculty to help yourself, then the physical part is useless.

ENGLEMAN: Any questions or comments from members of the Commission? Thank you very much, Geraldine.

NEAL: Excuse me, I have my occupational therapist from General Rose with me. Could she say a few words, please?

TESTIMONY OF  
KAREN STRAWBRIDGE  
CHIEF OCCUPATIONAL THERAPIST  
GENERAL ROSE ARTHRITIS TREATMENT CENTER

STRAWBRIDGE: Mr. Chairman, members of the Arthritis Commission, I am Karen Strawbridge, chief occupational therapist at the General Rose Arthritis Treatment Center.

Geraldine Neal is one example of many who have been stricken with arthritis. She is a 24-year-old juvenile rheumatoid arthritic. During the past seven months, Gerry has had numerous hospitalizations and surgeries. The surgical procedures include the bilateral total hips, bilateral total knees, and a right total elbow. The cost for these hospitalizations was approximately \$25,000. This included the hospitalization, therapy, nursing, medications, etc.

It did not include surgeons' fees, nor does it cover outpatient therapy or additional costs for possible future surgery. As you can see the cost of treating this disease is overwhelming, but let me ask you, how much money is your functional independence worth? Have you given any thought to the simple tasks that you and I take for granted every day? For example, what if you couldn't stand up from a chair or sit down on a toilet? How would you get into your house if you couldn't independently turn a key or get into your car if you couldn't open the door? How would you feel if you couldn't reach your face to brush your teeth, comb your hair, or feed yourself? Would you go hungry because preparing the meal caused so much pain that you would just as soon forget about it?

These are just a few of the problems an arthritic faces every day. Several tasks become overwhelming obstacles because of pain and deformity. This is where our job as occupational therapists begins. We attempt to teach our patients to work within their limitations, work with what they have got. How can we teach the patient to be more functionally independent?

After multiple surgeries, Gerry does have more leg mobility and strength, but not enough to be independent in standing and sitting from a chair. So we got her a catapult seat which gives her the needed assistance and independence in doing this activity. There are adaptive devices and aids to help in all of the above-mentioned activities, but the majority of the patients know nothing of these. Instead they have no other choice but to become dependent upon family, friends to do simple activities.

Occupational therapists also construct splints to aid patients in functional activities and to prevent deformities. We teach strength protection and work simplification. Extensive training in activities of daily living is also done. And last, but not least, we work on general strengthening and range of motion in the upper extremities.

All of this takes time and money. In order for occupational therapy to offer the best in rehabilitative care, it is vital that we get additional training in all the areas of arthritis and related topics. More funds need to be made available for postgraduate study and clinical research.

Yes, this does take time and money, but it would be time and money well spent.

ENGLEMAN: Thank you. Regarding the basic education, I was wondering about your feelings on whether or not the occupational therapist is prepared to deal with the physical and emotional problems of the chronically ill, such as arthritis, in your basic training courses. Do you feel that they do need additional training and, if so, how would you recommend that they get that training? Where could they receive it?

STRAWBRIDGE: I strongly feel that we are not adequately prepared in this area, that we do need additional training. This is something that we would have to research and find courses. I am not saying I know where all the courses are offered but this is something that needs to be offered.

VOICE: Where did you learn all this about arthritis treatment with OT?

STRAWBRIDGE: I have done a great deal of reading, I have attended a few continuing education classes, but certainly not enough to feel adequate.

VOICE: Is this maybe on-the-job training? Would you say, in other words, because you are obviously working where there is an awful lot of arthritis and so because you are there, then in sort of on-the-job training is where you receive most of your help and interest in arthritis?

STRAWBRIDGE: Probably 75 percent, yes.

ENGLEMAN: Thank you very much. We now proceed to call on Miss Price. I think the program shows Miss Price is coming from a very well known community on the West Coast, San Francisco.

TESTIMONY OF  
NENON PRICE  
PATIENT  
SAN FRANCISCO, CALIFORNIA

PRICE: I would like to identify myself. My name is Nenon Price. I am a native Californian, and I am currently residing in San Francisco. I am also an extremely fortunate example of a person with arthritis.

My first exposure to one of the many forms of arthritis was over ten years ago. Scores of visits were made to medical specialists and numerous clinical laboratory tests were made before the final diagnosis of "Lupus" was made.



At that time, my doctors at Kaiser Hospital in Oakland asked Dr. Engleman to come in on the case as the consulting physician. Together they have all cooperated beautifully and jointly have utilized the laboratory facilities of both Kaiser Hospital and the highly sophisticated laboratory facilities at the University of California at San Francisco.

These past ten years have not all been a bed of roses, and at times my business and social life have had to take a back seat. I have experienced pain and substantial complications over the years. The worst two periods probably were the first year following diagnosis, and the second being about two years ago when my arthritis manifested itself in pleurisy. I was placed on substantially increased dosages of Prednisone and other medications. At times the side effects from the medications were worse than the pleurisy ....my hair fell out, I gained almost 30 pounds, and I became terribly depressed. Fortunately this last episode with the pleurisy lasted less than a year, and the side effects of the medication decreased proportionately with the lowered doses of medication.

One of my first concerns when I found out that I had arthritis had been how I was going to support myself. Fortunately I belong to a prepaid medical program so, except for drugs, my medical bills are minimal. But also I work for a company, D'Arcy Advertising, which has stood beside me at all times. During that year when I was so sick, I worked only when I was feeling well enough. It was very important to me to be able to have a change of scenery from my apartment and the doctors' offices... in addition to some outside responsibility. Without the job and support of my employers, I just couldn't have done as well.

It was also a difficult time for D'Arcy because they never knew when I'd be at work or in what kind of shape I'd be in if and when I got there. I don't know how well most employers react to the problem of their employees having prolonged illnesses, but D'Arcy went out of its way to be understanding and generous. Even though I worked maybe only half time for about six months during this period, I never lost any wages. I feel that this shows an excellent example of a company's responsibility and concern for an employee. I'd hate to think of the number of companies who wouldn't allow an employee to remain on full salary over such an extended period.

I do know that approximately 3.5 billion dollars in wages are lost annually by arthritis victims. I am sure that compensation for these lost wages is a very real worry for many arthritics...and worry is something that none of us needs.

Now the symptoms of rheumatoid arthritis can obviously be treated successfully and the progress of the disease can be halted, but there are still too many unanswered questions about the cause, cure, and prevention. I don't expect to have a trouble-free future, but I do know I will continue to benefit from excellent medical care.

Someday there will be answers to all the questions surrounding arthritis. And now we all have the responsibility to support and encourage the continuing in-depth clinical research on arthritis and the increased awareness of arthritis and its symptoms for the general public.

Everyone who suffers from rheumatoid arthritis should receive the same excellent treatment and care that I currently enjoy. If they don't now, then they are being short-changed. It is also the responsibility of all of us to make sure that all arthritics receive the best treatment known, regardless of their circumstances.

As I appear before you today, I hope that you realize that early diagnosis and continuing proper medical treatment can be of tremendous benefit to the patient. I have never required prolonged hospitalization, and I have no permanent disability.

In summarizing my experiences with arthritis, I feel very encouraged about my future. I lead a perfectly normal life, I feel fine most of the time, I hold down a full-time demanding job for an advertising agency, I have my own apartment, and I have a normal social life. Something really can be done for the arthritis patient....it's been done for me....and it should be done for all others!

ENGLEMAN: Thank you very much, Nenon. Thanks for the plug. Any comments from the Mayo Clinic?

We will now continue to the next group and ask Dr. Robert Cathcart to come up, along with Drs. Harry Ward, John Ward, Mack Clayton, Miss Elliott, and Dr. Steigerwald. The next group of witnesses will focus on the needs in relation to medical education and research. I will call first on Dr. John Ward.

TESTIMONY OF  
JOHN R. WARD, M.D.  
PROFESSOR OF PREVENTIVE MEDICINE  
DIRECTOR OF THE ARTHRITIS DIVISION  
UNIVERSITY OF UTAH COLLEGE OF MEDICINE

WARD: The charge of the National Commission on Arthritis and Related Musculoskeletal Diseases to develop a plan for a comprehensive attack on arthritis is a formidable challenge. I assume that the plan will include recommendations for new programs of professional and public education, basic and clinical investigation, and development of methods for improved patient care at the community level. The dilemma is how to achieve these goals in the most effective and efficient manner. I sincerely appreciate the opportunity to express my views on how such an effort might be most successfully implemented.

The plan should concentrate on the development of Arthritis Clinical and Research Centers. These centers would have a number of objectives which would translate into programs to improve our knowledge and understanding of the etiology, pathogenesis, and treatment of the major forms of arthritis. The ultimate goal would be the prevention and/or care of the common forms of arthritis.

Because of the sophistication required for innovative basic and applied research, no one center would be able to meet all objectives. Each center would have unique attributes of personnel and programs so that



one center might concentrate on research aimed at understanding the inflammatory process in hopes of designing specific interventions. Another center might search for an infectious agent which could cause rheumatoid arthritis. Another center might develop a research program for improved patient care at the community level. These examples could be greatly expanded but emphasize the complexity of the problems.

Each center would incorporate educational programs. The specifics of the educational objectives would vary greatly and would include development of basic research scientists, training rheumatologists for applied research and patient care, education of practicing physicians for improved care of patients with arthritis, and training of allied health professionals.

Most, if not all, centers would develop programs to improve patient care. This implies that such centers will have active clinical programs for accurate diagnosis and exemplary care of patients with arthritis.

A number of centers are currently in operation but limited and uncertain funding impedes achievement of their full potential and productivity. Nonetheless, these centers have programs, personnel, and other resources that can be readily expanded with minimal time constraints. With assurance of long term support their contributions can be assured.

While I have promoted the center concept, a word of caution is in order. It would be unrealistic for each center program to have high quality and productive programs in all areas of activity. Thus each center would have a set of different primary objectives in addition to common activities dependent upon personnel, facilities, and geographic location.

A system should be developed for communication and coordination of center activities in order to avoid unnecessary duplication or delay in dissemination of important observations. How to accomplish this goal will require considerable thought and effort.

Geographic representation is important. For example, in the field of patient services, the urban-rural society and systems can best be accomplished in centers located in this setting; i.e. Denver and Salt Lake City. Other centers would be strictly urban in their activities.

Finally, I would recommend that the Commission emphasize the concept of high quality and productive effort. This suggestion implies that a limited number of centers may be more desirable than a large number of centers with limited resources. What the balance should be will require careful planning and remarkable judgment.

[Start of new tape - testimony interrupted.]

ENGLEMAN:...only a few comprehensive centers that would incorporate every aspect of the problem, is that correct?



WARD: No, what I intended to state was that perhaps a smaller number of centers with adequate resources would be more desirable than a large number of centers. But I emphasized that not all centers can do everything; that one center would have unique attributes that would be specific for that center's personnel, facilities, etc.

ENGLEMAN: Is there any one attribute that you think should be a common denominator for all?

WARD: I think there should be one attribute, namely, a patient care program as a basis for training, education, and, I think, direction at research effort as well.

ENGLEMAN: So the patient care program would be the key, and then everything else would be in terms of patient care, including research?

WARD: Not necessarily, no. I want to be certain that you understand that I believe a patient care program is an important component, but one center might have such excellence in research that their research endeavor would overshadow the patient care component of their activities. Another center might have such superb patient care facilities that their effort can lead to new knowledge in systems of health care, innovative treatment of rheumatoid arthritis, with very little bench research. So that I'm talking about centers, many of which have different programs, with a common thread of patient care and education.

ENGLEMAN: As you are aware, one of my concerns is, of course, the allied health professional and the hope that he can have a place to receive the kind of training he needs to deal with the chronic disease. My concern is (if we have just a very few centers) with the distances they may have to travel to find a place.

When you say "small numbers," could you comment further on what you mean--three or four in the country?

WARD: That's difficult. There are finite resources, and the point that I would like to make is that it is far better to have high quality programs that produce the optimal output in preference to a number of programs of lower quality with lower output, but larger numbers.

ENGLEMAN: Yes, Dr. Weaver.

WEAVER: Well, I'd like to press on with Dr. Ward a bit more on centers. I think we all have some visualization of the ultimate center as having components of research, patient care, patient education, postgraduate continuing education for physicians, and so on.

When you add up the cost of all of these activities, you can get to some rather staggering amounts. And, as you know, we have looked to the Federal Government for support along these lines in various other activities, but nowadays we're also beginning to be impressed that there are finite limits to the amount of the Federal contribution that can be made.

I wonder if you have had time to think about how we might begin this expanded program of comprehensive centers. Would you think of a number of half a dozen or a dozen, and then slowly expanding over time?

And the other question is, do you conceive of the possibility of joint or cooperative financial support between Federal grants and state and local activities and, perhaps in certain localities, sizeable private contributions as a means of reaching the sums that are really required?

WARD: First of all, I think one has to guard against what is pragmatic and what we would like. If we were to have the comprehensive programs, we would be, basically, setting up a series of NIH institutes throughout the country, which is obviously not realistic.

The point that I would like to make is, again, that we should guard against the concept that every center should have attributes in every sphere of activity--in essence, the constraints of personnel, space, and money make that, I think, a difficult goal to achieve.

What I was hoping to present was the concept that the centers would have a charge for some research, education, patient care, et cetera, but that one center might have a level of sophistication and expertise in one area; maybe it's community health services. Another one would have primary sophistication in basic research with far less activity in another area.

Now, in terms of the number of centers, again, I believe that it would be far wiser not to have too few or too many. An off-the-top-of-the-head figure might be something like 20, 25; I'm just guessing at this.

WEAVER: That's fine, thank you.

TESTIMONY OF  
H. ROBERT CATHCART  
CHAIRMAN-ELECT  
AMERICAN HOSPITAL ASSOCIATION

CATHCART: I am H. Robert Cathcart, chairman-elect of the Board of Trustees of the American Hospital Association, representing almost 7,000 member institutions such as home-care programs, nursing homes, and most of the nation's hospitals.

Today I am pleased to have the opportunity to appear before this Commission to discuss the problems of arthritis and muscular-skeletal diseases and the ways in which this nation can develop and support plans and programs to combat these diseases.

A review of the plan outlined in the legislation which authorized the Commission on Arthritis has identified for us a number of areas where personal health care institutions can have impact on the arthritis problem. The American Hospital Association strongly stresses the need for (1) testing and case finding; (2) evaluation and demonstration of preventive, diagnostic, therapeutic, rehabilitative, and control

approaches to arthritis; (3) the importance placed upon home care; (4) the essential need for rehabilitative facilities; and (5) the emphasis placed upon the organization and training of teams of health professionals (including allied health personnel) in the treatment and rehabilitation of individuals suffering from arthritis.

We do believe it is essential that the health care institution be the base for these types of programs. The medical center or multiprogram hospital can provide not only a physical base but also integrated care provided by available health professionals. Education should be coordinated with education about other diseases, and staff training should be multiprofessional.

Centers for treatment and study of arthritis and related muscular-skeletal diseases should be integrated into existing comprehensive medical facilities. Thus, program planning and financial support should be directed so as to support arthritis activities in comprehensive centers, avoiding the costly mistakes of placing these affairs in isolated or specialty institutions.

Arthritis is often accompanied by other health problems and illnesses. It is one of the major diagnostic groups now treated in hospitals on both an inpatient and ambulatory basis. In addition, arthritis is an illness which carries with it social and emotional components which must be considered as it is studied and treated. Again, the multidisciplinary staff of the hospital is the most likely place to develop these services. It must be recognized that Arthritis Research and Treatment Centers programs, as developed and supported by the Arthritis Foundation, will need to be increased and given greater financial and professional support if we are to achieve substantial improvements in this area.

The American Hospital Association has emphasized for a number of years the importance of coordinated home care programs. Home care is a viable alternative to institutional care in the study and treatment of arthritis and should be given greater emphasis. However, two factors will have to be considered in providing this home care. The first is, of course, adequate financing of home care programs, whether hospital based or freestanding with strong hospital linkages. All of us should work toward the inclusion of home care benefits in health insurance programs so that this care can be offered early in the course of disease. The second factor, which also will need increased emphasis, is the support of the concept of home care as an appropriate source of care. This means acceptance of the concept by physicians and other health professionals and their active involvement not only in getting the patient to the home care program but a willingness to participate as care givers in the program.

The provisions in the Plan relating to patient education and public education are of particular concern to us. Health education, and specifically patient education, are activities which the association is strongly supporting. We are developing excellent programs in these areas. Individuals with arthritis are one of the groups we have identified as needing increased patient education. Together with local Arthritis Foundation chapters we anticipate hospitals can, with adequate financial help, accomplish much in this vital area.



To summarize, we recognize arthritis as one of the leading crippling diseases, often chronic in nature, affecting young children and young adults but also a very difficult problem for the aging. It can best be handled through comprehensive, multidisciplinary research and care, focusing not only on the physical, medical factors, but on the social and emotional components of behavior and care. These services must, we believe, be based with provider institutions that manage a wide range of health and medical services. The development of single disease or categorical service centers is to be avoided.

Increased support through funding of research, multidisciplinary care, and education - public and professional - is essential if this serious disease, affecting large numbers of our population, is to be combated. The association and its members are involved and wish to remain so.

Thank you.

ENGLEMAN: Thank you, Mr. Cathcart. As the President-Elect of the American Hospital Association, what is your attitude towards the teaching hospital, university hospital, or the community hospital as a base of operation, or do you have any strong feeling about this?

CATHCART: I guess we have to define what a teaching hospital is, and I think I'm not going to have a definition that...

ENGLEMAN: Well, for the sake of this discussion, let's say a medical school.

CATHCART: Well, since there are only 114 medical schools, I guess that's too narrow a base, and certainly in the Rocky Mountain areas where there are some states without medical schools, I think that would be an unfortunate screening device.

It can be used as a screening device, and I think we also have to be candid in acknowledging that some of our teaching institutions have not been relating to their constituency--their patient service constituency. Some of them have, and some of them have not. I think the teaching hospitals have some similarities, but they're also a heterogeneous group, and I think it would be a mistake to use that only as a screening device.

ENGLEMAN: Some of the community hospitals presumably do not have professional people who are interested and have a background in arthritis.

CATHCART: Absolutely, and some teaching hospitals don't either.

ENGLEMAN: That's very true, unfortunately. Any other comment? Thanks very much Mr. Cathcart.

We have another Ward on the panel here, so I will at this time call on Dr. Harry Ward.

TESTIMONY OF  
HARRY WARD, M.D.  
DEAN  
UNIVERSITY OF COLORADO  
SCHOOL OF MEDICINE

WARD: I'd like to thank you, Mr. Chairman. I am the second Dr. Ward; I'm Dr. Harry Ward, and I'm the Dean at the University of Colorado School of Medicine.

As I sit here and listen, I think that expectations, hopes, ambitions for the National Arthritis Act are going to significantly outstrip the amount of available dollars.

I would like to limit my remarks to two areas: first, the concept of the arthritis center as seen by a medical center manager, which I consider myself; and second, the concept of research funding.

As far as the arthritis center--I embrace the concept of a center, but, as I stated, I am concerned about the difference between expectations and the available dollars. I believe that this Commission, when you establish centers must, number one, insist that each center define precisely its goals. I think we've already heard today that there are a number of approaches to this.

I would be surprised if, with the limited funding that is available, you will be able to achieve the core goals and the supplemental goals in each center, as defined by the National Arthritis Act.

I think that Dr. Whedon asked the question, what might be a fundamental core goal of a center.?

Whether all centers are the same, or whether there will be separation of types of centers, I believe that the major core goal of the majority of the centers should be: (1) research; and, (2) education. And I'm going to explain why I feel this way in a moment.

Let's specifically discuss research. I think that the research should be both basic and clinical.

As I look at the future, I believe that there will be sufficient patient care monies available for major service components in health care delivery in this country.

As we have looked at the education of medical students, I think that we will start seeing increased student fees that will largely offset institutional costs for education. I'm really concerned that the major supporter of research in arthritis must be, and will continue to be, the Federal Government. And, if we do not protect this as a major goal of the arthritis centers, I believe we've lost a future opportunity.

I would include in education both the education of physicians of allied health categories and the education of investigators. I believe

that one of our major manpower shortage areas is adequately trained, high expertise investigators.

The secondary goals (and I would wish that these were not secondary goals, but, if we accept that there will be a limited amount of funding, I would suggest that they would be secondary goals) will be continuing education programs, informational programs, screening, referral systems, et cetera.

The second item that I would like to discuss under the arthritis centers is the structure. I would hope that the Commission will insist that the structure of an arthritis center should be explicitly defined.

I think that the major investigator--the principal investigator, the executive of the arthritis center--should report directly into the office of the chief executive of that institution or the consortium of institutions.

I think that you should insist that the arthritis centers should be interdepartmental and, in many cases, interinstitutional.

I would submit that you will find that there are institutions in which it will be suggested that the arthritis center will exist within one of the traditional academic departments. I would urge that we should insist on interdepartmental effort, because the effort should be toward musculoskeletal disease, which includes surgical fields; certainly the fields of rheumatology and immunology; we've heard about the behavioral sciences; etc. So, it must be an interdepartmental, interinstitutional program.

The next item that I would like to mention under the arthritis center is the concept of core funding.

As an institutional manager, it is very difficult to have an established funding that is year-to-year renewable, in which an institution cannot make hard-headed, long-term, future plans. I would urge that a core-funding concept be established with approximately a three- to five-year core funding, which would allow institutional planning and regional planning.

The second major item that I would like to address is my hope, my wish, that you will keep high in your priorities that we must protect research funding. If I understand the hypothetical funding of the National Arthritis Act, it is expected that approximately 70 percent of the funding will be used for arthritis centers. I would urge you to protect that remaining 30 percent--I would urge you, as I have, to include in the arthritis centers some funding, some core funding, for research because I really do feel that in the future the major research funding of this country is dependent upon the Federal Government.

We will be able to fund health care from fee systems, from national health insurance systems. We are funding major educational programs by student fees, and the Federal Government must accept as its major priority, funding for funding our research programs.



Thank you.

ENGLEMAN: Thank you, Dr. Ward.

GAY: Dr. Ward, whenever someone talks about manpower, someone always says how many. Can you give us any minimum numbers, or any formula that might be useful in arriving at that?

WARD: You mean the numbers of centers, or the manpower that is needed?

GAY: (INAUDIBLE)... and training, and speaking in particular of the investigators you referred to.

WARD: I don't have that information, Dr. Gay. I'm sure it is available. I can say, from our own experience with recruitment in this field to staff fundamental research programs in arthritis, that I have been very disappointed with the size of the pool, and I think that we must make major efforts to expand and broaden this pool. But I don't have the specific numbers.

VOICE: Dr. Ward, might I draw you out a little bit on this interesting concept you advanced of distinguishing, in the supportive centers, a core support that would extend over three to five years. Would you look at that under higher magnification and suggest to us what you regard as the elements of the core?

And, secondly, I was interested to hear you touch on the gain from this concept to enable you to do more with planning with the community. And, again, that's another area where if you care to supply any details for me, it would be helpful.

WARD: I think we would have to spend some considerable time in working out the total structure, but I would look at some core funding of an administrative staff; secondly, as research support; and, thirdly, for educational programs, and I think the first step would be education of investigators in musculoskeletal disease, sort of specialty fellowships. On the top of that core funding, the center then could apply for, in a competitive way, a special outreach program, a special program in continuing education, a special program, perhaps for undergraduate research support, etc. But I would look at those on the top.

I think that many of the service programs also should be added on the top of this core and that the institution will then have to identify some shared resources that would help fund these special service programs. So, perhaps there might be a special rehabilitation center, let's say, developed but the arthritis center grant would show that there is offsetting revenue from patient care money, perhaps from private given money, with only a small portion of that particular rehabilitation center provided by the Federal Government.

VOICE: Thank you.

WARD: So, it's sort of a sandwich technique.

VOICE: Dr. Ward, I recently read an article where a spokesman for the American College of Surgeons indicated that perhaps we had too many surgeons in the country, and, of course, at all of our hearings we have heard about the need and recognize the need for more rheumatologists, and I was wondering, as a Dean, if you have any thoughts as to how we can encourage more going into this field rather than into surgery?

WARD: Let my answer show that I am not necessarily agreeing that there are too many surgeons. Now, it's not necessarily true that I don't agree that there are too many surgeons, but I would rather not enter that.

A state educational system is moving its educational programs in the residency health staff field into the arena of family medicine.

You read of ambulatory care. As you know, the American Association of Medical Colleges, the Council of Deans, recently endorsed the concept that 50 percent of all health staff residency slots should be in family medicine, general internal medicine, the general field of pediatrics. Specialty programs are being phased out by the Federal Government, as well as by the states.

The need for more rheumatologists, I would (INAUDIBLE) — special emphasis is made to include that as a goal of the National Arthritis Act. The need for more rheumatologists that you've identified, that we've identified, is a claim at the same time that the Federal level is removing such support and the state level is removing such support. So, I think that we need specific financial support for the slots--for the positions for these kinds of students--for the postgraduate physicians that will go into the field of rheumatology.

VOICE: Harry, I'd like to ask a different question. I don't know if you're the right one to ask, but what percentage of physicians in Colorado are graduates of the University of Colorado?

WARD: Approximately 60 percent of the physicians in Colorado are graduates of Colorado. However, approximately 40 percent of all of our graduates stay in Colorado, and overall around 60 percent are Colorado students. We are a state that imports at least 40 percent of our physicians, and we certainly are a state that shows that health education is a national effort, must be a national effort.

ENGLEMAN: Do you want to follow that up, Dr. (INAUDIBLE)?

VOICE: No, no.

ENGLEMAN: You must have had a good reason for asking that question.

VOICE: That'll come out later.

ENGLEMAN: Thank you, Harry.



TESTIMONY OF  
MACK L. CLAYTON, M.D.  
ORTHOPEDIC SURGEON

CLAYTON: My name is Mack L. Clayton. I am an M.D.-Board certified orthopedic surgeon with offices at 2045 Franklin, Denver, Colorado 80205, with a special interest in arthritic surgery. Eighty percent of my practice involves surgical rehabilitation of arthritic patients. I have published over 20 articles on arthritic surgery and have devised surgical procedures. I have been a member of the Committee on Arthritis of the American Academy of Orthopaedic Surgeons from 1961 and was Chairman of the committee from 1966 to 1969. I am a member of the American Rheumatism Association and was Second Vice-President in 1973. In 1968 I was Chairman of the Arthritis Task Force of the Academy and presented a report regarding arthritis and the orthopedic surgeon in the future. I am also a member of the American Society for Surgery of the Hand. I have been active in the establishment of the Arthritis Treatment Unit (part of a center) at General Rose Hospital in Denver and was the orthopedic consultant to the Arthritis Clinic of Dr. Charley Smyth at the University of Colorado Medical Center for 20 years. Here we developed a multidisciplinary team approach to the care of the severely involved rheumatoid arthritic patient.

Rehabilitative surgery has been the greatest advance in the treatment of the crippled arthritic in the last 15 years and is the most rapidly expanding field in orthopedic surgery. The field was growing even before modern total joint replacement using "bone cement" for anchorage of components. This became generally available in 1971, and its use has escalated since.

When an arthritic joint has been destroyed and deformed beyond a certain stage, medical treatment is symptomatic only and surgical reconstruction is often indicated, depending on the patient's general condition. General medical treatment must be continued, particularly in the rheumatoid arthritic, as this is a generalized disease. Destruction of the joint cartilage is the common denominator of the end stage of various types of arthritics. Basic research by the orthopedists and rheumatologists into the various destructive mechanisms must be continued and supported if we are to improve our treatment as well as monetary support to gradually reduce the number of patients requiring surgery.

Clinical research must be continued and expanded to cover all aspects of surgical reconstructive procedures in rheumatoid patients. This should involve data recording from all aspects of a multidisciplinary approach including medical, surgical, research, and socioeconomic. This will involve additional health personnel to keep such additional records. However, these records will be necessary in evaluating the true gain to the patient for surgical procedures; e.g., How does it affect their overall way of life? How does it affect their income? What other form of therapy can take a patient with severe pain, almost unable to walk due to a destroyed arthritic hip, and have a total hip replacement performed and leave the hospital in two to two and a half weeks free of pain and walking on crutches; and then advance to walking without support in three months in 90 percent of the cases unless other joints are severely involved? The



surgery only represents one incident in the overall treatment of the patient, but it is a dramatic incident.

Although the benefit to the patient cannot be measured in dollars and cents, we really need to know how much treatment costs and what is the economic result over a long period of time for various operations. We also need to evaluate other nonoperative forms of treatment in a likewise manner. Funds for training allied health personnel such as nurses, physical therapists, occupational therapists, and social workers for this specialized treatment field of chronic arthritis are needed. These procedures cannot be carried out except with a "Team."

There are relatively few positions (about 15) in the country for orthopedic surgeons to receive additional training in arthritic surgery emphasizing a team approach. This is where the greatest advances in treatment are being made at this time and more orthopedic-arthritis fellowships are necessary and need supporting funds. (6 to 12 mo.)

I have personally supervised over 12 orthopedic surgeons in the last eight years and they are actively engaged in this field. No arthritis treatment center should be approved without an orthopedic surgeon, and certain centers should provide advanced treatment in orthopedic surgery -- including hand surgery, which is now so important in the new developments. Funds for continuing education (up-dating) for practicing orthopedic surgeons should be provided, and this would also be a function of the center.

Facing the facts, it will be a number of years before a "cure" is found. Eventually, when rheumatoid arthritis is controlled, there will still be other forms of arthritis needing surgical treatment. The orthopedic surgeon of today has earned his position on the "team" and should be included and expanded in the future plans for treatment and research of this greatestcrippler, "arthritis."

In conclusion, a good motto for all involved in arthritis is:

Strengthen the weak hands  
And make firm the feeble knees  
Say to those who are of a  
Fearful heart,  
Be strong--Fear not.

--Isaiah 35.

SUBMITTED STATEMENT OF  
MACK CLAYTON, M.D.

This is the summary based on a complete report that Mack L. Clayton, M.D., assembled in late 1968.

This still represents my beliefs and feelings on the subject. I am enclosing the report exactly as I sent it at that time. The money accounts, of course, need to be changed, and also the numbers need to be

changed. The Commission has been given ample numbers and many figures in the late reports. This report also shows that this is a long-range plan and that it should reach culmination in the "National Arthritis Act." The complete report should be available from the American Academy of Orthopedic Surgeons through President Dr. Wm. Donaldson as desired. This is about three times the length of the summary I have submitted.

If I can answer any questions related to the written report, I would be glad to do so.

#### Report of Arthritis Task Force, Services Section

This report will deal with arthritis in relation to orthopedics with the past history, current status of arthritis, to derive needs for orthopedic services in terms of scope with a listing of unmet needs and obstacles, and list plans for orthopedics as related to arthritis in the future.

#### I. History.

Although arthritis is the oldest known chronic illness, agreement on classification has only been in the last 25 years. Orthopedic surgeons have always been concerned with arthritis and were the major treating physicians to arthritics until the 1930s when with increasing knowledge of the systemic nature of rheumatoid arthritis, a subspecialty of rheumatologists arose from internal medicine. In 1935 the American Rheumatism Association was organized and today numbers 2,845 members. The Arthritis Foundation, a voluntary nonprofit health organization, was founded in 1948. In 1965 the American Rheumatism Association became the scientific arm of the Arthritis Foundation. In 1943 Dr. N. M. Smith-Petersen<sup>5</sup> first said that surgery should be performed in certain early active cases of rheumatoid arthritis to prevent further crippling. In 1961 the American Academy of Orthopedic Surgeons formed a Committee on Arthritis, whose function is education, and this Committee is to improve the orthopedists' education in arthritis and to orient the general physicians to the role of orthopedics in the treatment of arthritis and encourage orthopedic research in the arthritides. This has fostered setting up many multidisciplined "team approaches" to the problems in many centers. This Committee has resulted in improved communications and cooperation with the rheumatologists. In 1963 a conference on "Criteria For and Evaluation of Orthopedic Measures in Rheumatoid Arthritis" was held in New York City sponsored by the Arthritis Foundation, American Rheumatism Association, and National Institutes for Arthritis and Metabolic Diseases. In 1968 an Arthritis Foundation Committee is conducting a controlled clinical trial in rheumatoid arthritis to test the effectiveness of early synovectomy in halting the disease process in operated joints. At the present time the role of the orthopedic surgeon in the treatment of the arthritides and rheumatoid arthritis is increasing.

#### II. Current Status of Arthritis to Derive Needs for Orthopedic Services in Terms of Scope.

Arthritis<sup>7,8</sup> is an illness that affects more people and causes more crippling than any other chronic disease (16,800,000 Americans) and over 3 million report it limits their usual activity. All ages are affected. Because the arthritis that affects the young is the most crippling (rheumatoid) many of the 198,000 affected youngsters will be handicapped for the rest of their lives. As a source of disability, arthritis caused about 200,000,000 days of restricted activity including 57,000,000 days of bed disability and 12,000,000 days of work absenteeism. Arthritis is responsible for an estimated 1,500,000 days of hospitalization and 30,000,000 visits to a doctor per year (not including patients in nursing homes<sup>8</sup>). The annual costs follow. The measurable costs of arthritis reached an estimated \$1.7 billion<sup>7</sup> per year in 1963.

Loss of productivity for working people	\$220 million
Disability payments to arthritics from Social Security, Disability Insurance and Welfare	132 million
Loss in productivity from disability payment group	300 million
Hospitalization for arthritis	60 million
Office visit fees to doctors and physical therapists	150 million
Nonprescription drugs and devices to relieve pain	435 million
Loss of Federal and State income tax	3.6 billion
Premature death from rheumatoid arthritis	49 million

Arthritis has its greatest impact on the lower income groups<sup>3,7,8</sup> and the incidence is higher. In contrast to the killing diseases, arthritis creates a cumulative socioeconomic burden. Gradually it withdraws from productive activity large numbers of otherwise capable people who become dependent upon other family members or community agencies.

The Public Health Service estimates there are 3 1/2 million persons with definite rheumatoid arthritis, a generalized chronic inflammatory disease of unknown etiology. Total disability usually comes at a lower age than osteoarthritis<sup>6</sup> and involves females 2:1<sup>4,8</sup>.

This is in contrast to a cost of existing arthritis programs estimated at \$26 million annually<sup>7</sup>.

Osteoarthritis (degenerative joint disease) involves 9 to 10 million people and is a chronic arthropathy with degeneration and often hypertrophy of bone. It usually affects the older patient in weight bearing joints and causes total disability in fewer patients and at a later age<sup>6</sup>.

Gout<sup>8</sup> is a metabolic disease characterized by intermittent bouts of acute painful arthritic attacks and accompanied by hyperuricemia. One hundred thousand to 200,000 persons report annually that they have the gout and it is responsible for 2.6 million days of restricted activity.<sup>8</sup>



Ninety-five percent of the patients are men, and onset is most common in the 4th and 5th decades.

### III. Current Status for Meeting Needs.

At the present time there are 4,000 certified orthopedic surgeons and an estimated 4,000 uncertified physicians doing orthopedic surgery. The American Rheumatism Association has 1,850 members (about 100 are certified orthopedic surgeons). These two groups provide the key personnel in treatment teams for rheumatoid arthritis. Physical medicine specialists and numerous paramedical personnel are involved, e.g., physical therapists, occupational therapists, nurses, and vocational rehabilitation in particular are available for services.

There are about 50 first-rate arthritis research-training care centers and more than 300 clinics in the United States. The research-training-care centers are usually university centered and have primarily a teaching and research function and do not provide care services for large numbers of patients.

The arthritis clinics are scattered, but most are in large centers. The Arthritis Foundation Chapters help support many of the clinics, many of which are mobile physical therapy units.

Research in arthritis is all centered in the 50 research-training-care centers. About \$15,000,000 is spent annually for research and training. Two-thirds of these centers have organized multidisciplined approaches and provide better training for total care. Only about eight positions are available for graduate fellowships in "orthopedic-rheumatology."

There are numerous postgraduate courses in arthritis annually. Instructional courses have been held at the American Academy of Orthopedic Surgeons meetings for over 10 years.

### IV. Unmet Needs and Obstacles.

The greatest unmet need is adequate (including early) treatment to which the obstacle is the lack of knowledge of the etiology and specific cure for arthritis. Also, the lack of knowledge as to the cause of cartilage destruction which is the common denominator of disability in arthritis and further research regarding this is necessary. The treating physicians are not well educated and oriented regarding arthritis and the patients are not referred for expert consultation at an early stage.

The lack of easy availability of experienced consultants. There are relatively few centers with an organized multidisciplined approach to the severe arthritic and limited numbers of patients can be treated; long distances may make these relatively inaccessible.

Physical therapists, occupational therapists, and nurses are necessary in comprehensive care in the hospital, outpatient, office, and home. They often do not have the specific treatment necessary for dealing with severe rheumatoid arthritis.

There are relatively few hospitals with adequate rehabilitation type sections in which arthritic patients can be hospitalized for treatment utilizing the physical medicine department, X-ray laboratory, but having semiambulatory quarters available at less expense.

Another of the unmet needs is the ability to keep the arthritic productive at optimum capacity. It is difficult to find a job suitable to the patient for many employers are not inclined to hire an arthritic patient. Job retraining is often necessary, but finding a job afterward is often difficult. The housewife is most commonly affected and this disrupts the household.

Patients often have financial difficulties with hospital and medical bills because of the chronic nature of the disease and often they cannot obtain health insurance.

With the shortage of medical personnel, there is an increasing use of paramedical personnel, but the prescribing treating physician is still held legally responsible.

Specific splints designed for the arthritic patient, particularly the rheumatoid, should be devised.

#### V. Alternate Plans.

Alternate plans are not discussed in this short form.

#### VI. Strategy.

Regional Arthritis Centers could be set up on a geographical and population basis utilizing the present existing training-research-care centers and adding others. Expansion would be in three areas: (1) additional laboratories for research into the basic cause of the arthritides and cartilage destruction and a suitable prosthetic substitute for cartilage, (2) establishment of treatment facilities for ambulatory out-patient and long-term hospitalized patients, (3) expanded training of medical and allied personnel to provide adequate treatment of arthritic patients.

Concept and organization of a regional rheumatic disease service unit is depicted in Exhibit A.

The Arthritis Center would be an organizational federation and not necessarily be housed in one place. The uniting force would be administration function to integrate services of the individual units and the overall purpose of the Arthritis Center would be rendered to provide the highest quality total medical and rehabilitative care possible for the arthritic patient. Combined efforts of individual organizations, tax supported and private would be necessary.

The Arthritis Center would be administered through the Arthritis Foundation, local chapter and would take care of: (1) planning and contracting with existing facilities to provide programs and services for arthritic patients, (2) serve as the fiscal agent for obtaining and

distributing funds from public and private sources, (3) provide sources for treatment and/or research for education, lay and professional.

Education (probably university based) would be to (1) expand the present knowledge of diagnosis and treatment, (2) utilize short intensive courses for practicing physicians, (3) clinical hospital clerkships for frequent four to eight weeks of intensive instruction in total care of arthritis, (4) teaching clinics and conferences at regular intervals in hospitals throughout the area coupled with local societies. Physicians in the center would travel on a scheduled basis, (5) closed circuit T.V. and audio-visual programs would be provided for regional hospitals, (6) train clinical investigators and academic teachers in the field of arthritis, (7) medical assistance for specific training courses oriented to nurses, medical technicians, vocational counselors, physical therapists, social workers and hospital administration should be developed, and (8) undergraduate medical students should have scholarships for off-quarter basic research of rheumato-orthopedic problems and scholarships for clinical experience in multidisciplined rheumatoid orthopedic problems should be developed.

New manpower is needed in departments of the medical schools in research such as biochemistry, cellular biology, immunology, pathology, pharmacology, and microbiology. Research laboratories for rheumatic disease and/or orthopedics should be coordinated.

Expansion of clinical research training should be done emphasizing multidisciplined approach.

Central treatment units (probably nonuniversity bases but nearby) would have the primary objective to give the best available treatment to patients with arthritis to alleviate the suffering, reduction of disability, and total rehabilitation by multidisciplined approach. A rheumatologist or orthopedist could be the Chief of the center according to individual qualifications and the other would be the assistant Chief and they would see all the patients together with other ancillary personnel. A pediatric consultant should be available for children. Adequate treatment programs would be instituted with all measures and surgery utilized as indicated at its proper timing in the overall long term treatment plan. The patient would be transferred to the regular acute section of the hospital for surgery and back to the chronic section as soon as possible before discharge. Offices and treatment facilities for both outpatient and hospital patients would be required. The structure should be immediately adjacent to an existing acute hospital where the patient would have all of these services available, but basic facilities should provide low-cost beds and motel type services for ambulatory-type patients (rehabilitation service). It must be in close proximity to the physical and therapy unit of the hospital.

Education facilities of the treatment unit would serve as a teacher center for teaching graduate physicians, clinical fellows in rheumatology and orthopedics and ancillary paramedical personnel. The entire staff would be available for conferences and clinics in hospitals through the Center area.



In the treatment unit (1) Clinical research would be conducted as an experience in low-cost chronic disease care. (2) Follow-up studies in various long-term therapeutic programs involving drugs, physical therapy modalities, and orthopedic procedures (for instance synovectomy); also functional economic gains could be measured and evaluated. (3) Exchange of patients with specific research interest with the university based clinical center could be fostered. (4) Development of improved splints, braces, and appliances could be undertaken. (5) Multicentered information could be gathered and computerized.

Other treatment centers in the small arthritis units would be developed in existing private hospitals or rehabilitation facilities and would be staffed by either a physician or an orthopedic surgeon with specific training in rheumatoid diseases. Traveling teams of orthopedic surgeons and rheumatologists would make scheduled visits once or twice a month working with the responsible family physician. This provides expert local services for early diagnosis and early adequate therapy before severe disability occurs. Transfer to the specialized care center would be easily arranged. Mobile physical therapy units could be provided in the margin communities and on a traveling basis.

Legislation should be provided to give adequate protection to the physician with the increasing necessary use of paramedical personnel. The Arthritis Center concept is the best answer to the unmet needs and has plans for overcoming each individual obstacle.

If one year of productive time could be added to each severe rheumatoid or osteoarthritic, it would save the economy \$220,000,000 as well as the benefit of relief of pain to the patient. This is minimal, but it is estimated the Arthritis Center concept could add an average of five years to each severe arthritic and this would total \$1,200,000,000 to the economy.

## VII. Task Force Summary.

### A. Services.

1. Manpower consists of about 4,000 certified and 4,000 noncertified orthopedic surgeons and 2,850 rheumatologists plus physiatrists and numerous paramedical personnel, physical therapists, occupational therapists, nurses, and social workers
2. Resources -- \$645 million a year is spent for hospital, medical, and drug services. Care centers, a number of which have a multidisciplinary approach to arthritis; 300 arthritis clinics; interested and trained physicians' offices.
3. Ideas -- Alteration of present resources to have regional care centers to give better patient care and wider geographic coverage; plan to utilize governmental and private support as necessary.
4. See attached budget.

5. Education program for physicians and lay public on gout should eradicate gout as an orthopedic problem (and as a serious medical problem).

B. Education.

1. Manpower same as listed under services.
2. Besides the 15,000,000 research training grants, total \$527,000 spent by the Arthritis Foundation chapters for lay or professional education.
3. Increased education for medical and paramedical personnel and lay public through program of the arthritis centers on regional basis. Gradually this will give an increase in trained manpower.
4. See attached budget.

C. Administration.

1. Manpower -- Individual physicians; local boards of hospitals; Arthritis Foundation; governmental agencies.
2. Resources -- Research and training grants unknown. Usual estimate of 15 percent of total 25,000,000 to 2,225,000.
3. Ideas -- In regional center plans the Arthritis Foundation acts as administrator for governmental and private support for project; utilizes an existing agency knowledgeable and competent in the field; prevents duplication of services.
4. Budget -- Unknown.

D. Research.

1. Manpower -- Same as A-1.
2. Resources -- \$15,000,000 expended in 1968 for research in arthritis.
3. Ideas -- Further coordination of rheumatologic and orthopedic disease oriented research should help find etiology and cause of rheumatoid arthritis; find cause of cartilage destruction in arthritis.
4. How is a research budget ever justified in a cost basis by return in medicine?

Bibliography

1. The Arthritis Foundation: Twentieth Anniversary Report, 1968.

2. Murray, W.: American Academy of Orthopedic Surgeons Arthritis Committee Survey -- unpublished.
3. Public Health Service. Disability from Specific Causes in Relation to Economic Status. National Health Survey 1935 to 1936, Bulletin 9, 1938, Washington, D.C.
4. Short, C. L., Bauer, W., and Reynolds, W. E. Rheumatoid Arthritis. Harvard University Press, 480 pp., 1957.
5. Smith-Petersen, M. N., Aufranc, C. E., and Larson C. B. Useful Surgical Procedures for Rheumatoid Arthritis Involving Joints of the Upper Extremity. Arch. Surg., 46:764, 1963.
6. Social Security Bulletin, Department of Health, Education, and Welfare, 1962.
7. United States Department of Health, Education, and Welfare. Program Analysis, Disease Control Programs, Arthritis, September 1966.
8. United States Department of Health, Education, and Welfare. Arthritis: Source Book. Public Health Service Publication, No. 1431, 73 pp., 1966.

(Exhibit A, a graphic depiction of "An Arthritis Center for the (Blank) Area" is inserted here.)

ENGLEMAN: Yes, Dr. Polley.

POLLEY: Mack, I'd like to ask you to supplement your remarks about the cost of these procedures and the cost of funding, and so on. What procedures are underway by orthopedists for evaluation of the procedures?

CLAYTON: Well, I think this is underway. I don't know that there's any on a national scale--there are end result evaluations and forms, and this is a matter of individual groups. Here today, for instance, I know that Mayo Clinic reported on 3,000 total hip procedures a year-and-a-half ago, and they're trying to evaluate this. I don't know that anybody has made an economic study, except we have in very few patients. I know Ephraim Engleman, in California, and Bill Murray--one of their men spent six months with us, and he had looked up 1,500 total hip replacements in arthritic patients, and they had extensive data on these. It helps us improve our treatment. Now, down the road, I don't know of any studies that are being done of what the economics of an operation are.

ENGLEMAN: I apologize to Dr. Clayton and to our audience that the orthopedic member of our Commission is unable to be here today.

We'll now proceed to hear from Miss Jo Eleanor Elliott.



TESTIMONY OF  
JO ELEANOR ELLIOTT, R.N.  
PAST PRESIDENT  
AMERICAN NURSES' ASSOCIATION  
DIRECTOR OF NURSING PROGRAMS  
WICHE

ELLIOTT: My name is Jo Eleanor Elliott. I am a professional nurse, past president of the American Nurses' Association and of the Colorado Nurses' Association, and I am here on behalf of the Colorado Nurses' Association. I work for the Western Interstate Commission for Higher Education, headquartered in Boulder, Colorado. I work specifically with 158 collegiate schools of nursing in the 13 western states.

Over the past 15 years, a variety of major diseases/illnesses has each in turn had its "popularity" as a focus of national attention: mental illness and retardation during the Kennedy administration, heart disease during the Johnson administration, and heart disease, cancer, and stroke plus related diseases over the past ten years, these latter receiving major attention and action through the Regional Medical Programs. Arthritis has continued over these years to be a major crippling disease and morbidity-creating illness, but it has not had much "press." It has diminished in public appeal from earlier years, and is overdue for the attention and concern now to be addressed through Public Law 93-640, the National Arthritis Act of 1974. Clearly, these hearings throughout the United States will not only focus attention but hopefully will assist the National Arthritis Commission in determining priorities and in expanding on the potential of PL 93-640.

I state expanding on the potential because I am here to speak to needs in nursing and nursing education which will assist in carrying out the intent as well as the specific provisions of the law, namely to ensure that better health care is delivered to sufferers of arthritis and to ensure that the basic research into the causes of and treatments for the disease is continued and expanded.

Being the continual optimist, I am always surprised rather than being cynically certain of the fact when reference is omitted from such legislation as PL 93-640 to nurses or nursing's contributions to carrying out the provisions of the law. I read the law relatively carefully, and I found the word "nurse" included at least once! Euphemistically including nursing into phrases like "team" or "other health workers" denies the special contributions to the care of arthritis sufferers that nurses are making, but more especially that nursing can make in the future, care that can be increased given focused attention from those responsible for carrying out PL 93-640.

The impact of arthritis is on the whole family, not just the person affected by the disease. Nursing's contributions are in the arena of working with patients and their families who live with the disease daily, including early "case-finding" in the community. Nursing's goals are to assist the patient and the family to the optimum state of health and activity possible and to help minimize disruptions caused by the disease. The nurse is a key professional in working with the family in dealing with

the broad impact of arthritis - the psychological impact, the socioeconomic impact, life style changes, and on and on.

The decline in attention to arthritis generally has been reflected in that same decline in attention in schools of nursing preparing new nurses, in advanced education programs preparing nurses for specialized nursing practice, and in the omission from continuing education offerings of substantive programming in the area of nursing care for people suffering from arthritis. For example, in Colorado in the recent past there has been no specialized nursing preparation in the care of the patient with arthritis. Currently in the Adult Nurse Practitioner program there is some focus on arthritis. There have been only two graduates specializing in nursing of arthritis patients from the master's degree program at the University of Colorado School of Nursing.

Nurses need basic information about arthritis and its effect on the patient and family. There is, for example, the whole area of patient education, which tends to be woefully inadequate - information the patient needs to know about his disease, what is known by the experts, what is not known about the disease (this latter to decrease the preying by quacks on those with arthritis), information about activities of daily living, and about nutrition. There is research available in the nursing literature as well as in other fields on better ways to help patients learn. This research needs to be used and expanded to help those who live with arthritis to live better.

Nursing research - patient care research - needs to be addressed to other aspects of care of the person with arthritis. Patterns of nursing care delivery need to be studied, and the more effective ones disseminated broadly. We have little data on the nursing care needs of patients with arthritis, or whether the known nursing needs are being met effectively and efficiently.

Nurses prepared in primary care increasingly will be the first contact with the health care system for many people. Knowledge of early symptoms of arthritis and of the health and medical resources available to the patient are crucial to the maximum response for the patient from what is available from medical, nursing, and supportive services.

A strong case can be made - and I am among those to make it - for continuing basic research and on the causes and specific treatment of arthritis. But I urge those carrying out the National Arthritis Act of 1974 not to put all the eggs in one basket. We must enlarge the programs serving those people already suffering from arthritis. We need much more than treatment centers. We need teams of health care workers, and need financial support to field more teams, to give direct treatment. But, even more importantly, teams to work with patients and their families in the community.

The needs in the field of nursing to expand nursing's contributions in carrying out PL 93-640 include increased attention to the knowledge and care of patients with arthritis in every facet of nursing education and practice: basic nursing education, graduate specialization, research, continuing education and inservice training for practicing nurses, and

preparation of nurse practitioner specifically to work with patients with arthritis.

Rather than making a case for programming and support in each of the nursing areas, I propose the following areas of effort in priority sequence.

1. Demonstration projects

- a. in the uses of nurses and related personnel in health care delivery to patients and families with arthritis
- b. in early contact with patients to promote early entry into the health care system

Such demonstration projects would include outreach programs to patients in more remote geographic areas as well as continuing education for nurses in remote areas in the knowledge of the disease and in the care of patients who have arthritis.

2. Nursing research

- a. clinical nursing care studies to determine optimum ways to care for patients with arthritis
- b. studies of ways to get patients into the health care system
- c. use of various kinds of nursing personnel in care delivery
- d. patient teaching
- e. nursing education

3. Continuing education for nurses

- a. workshops for faculty teaching in basic nursing education programs so that new nurses have more knowledge than many have now (Faculty seldom teach very enthusiastically about things in which their own knowledge is limited.)
- b. workshops to assist faculty in planning for inclusion of content about arthritis and care of patients with arthritis in curricula in schools of nursing
- c. workshops and inservice for nurses who daily work with patients who have arthritis

4. Graduate education

- a. funds need to be provided for training support and to prepare specialists in nursing care of patients with arthritis and for nursing research in care of people who have arthritis.



- b. nurse practitioner programs should be supported in two to four schools of nursing across the country to prepare nurses to give care to people with arthritis, especially in the community and in out-patient settings.

5. Basic nursing education

In 15 collegiate nursing school centers across the country support the addition of one or two faculty members, specialists in arthritis, to work with the faculty and students and to develop teaching materials for use by both students and faculty and to be used with patients who have arthritis.

I propose a five-year plan of support for any area undertaken for support, with an assessment/evaluation of impact and effectiveness at the end of three years. Effective programs could be extended, others phased out.

Funds to support increased nursing efforts need to be specified for nursing, otherwise the funds will probably not be available. Basic research and medical treatment are more glamorous and attractive in competition for funds. I submit that nursing as an increasingly responsive and responsible discipline in the health care arena can and will make substantive contributions to this all-out struggle with arthritis.

In closing, I urge that attention be given to using existing and evolving health care delivery mechanisms such as public health departments, group practices, health maintenance organizations, and health service agencies rather than attempting to create new ones solely for patients with arthritis. We must build for long-range programming and financial support--far beyond what the National Arthritis Act of 1974 might provide or facilitate. Therefore, from the beginning we must take actions and initiate programs which will be carried on by those agencies and institutions in which we initiate programming.

Thank you for the opportunity to make this statement on behalf of all those people who have arthritis and on behalf of the discipline of nursing, which cares.

ENGLEMAN: Thank you, Miss Elliott.

VOICE: Miss Elliott, you mentioned one of the contributions of your profession would be early case finding, which certainly would be very important. We heard testimony from many patients who had years go by before their disease was recognized and properly treated. Do you have any ideas how this very important contribution could be encouraged and promoted?

ELLIOTT: I thought of one as I was driving down from Boulder. For example, I could see the use of the nurse/practitioner, particularly in assessing patients for arthritis in nursing home settings. I could see that kind of nurse, or the visiting nurse, or the public health nurse, making visits to senior citizens' centers, in which there might be opportunity for contacts. I can see nurses giving information to senior

citizen groups in terms of general health care and clues for the discovery of early symptoms of arthritis.

VOICE: I see. Okay, thank you.

ENGLEMAN: What percentage of the nursing schools is not associated with a medical school?

ELLIOTT: Only a very small percentage is associated. I don't have the percentages, but most schools of nursing are not in medical centers. Most medical centers do have schools of nursing, but we have about 1,500 nursing schools in the country. That includes associate degree, baccalaureate, and (INAUDIBLE) schools, and we have about a hundred and some odd medical schools, and in those medical centers, generally, there is a school of nursing also.

VOICE: May I ask, has your school made some start along the lines that you suggested in your five-point program?

ELLIOTT: I'm not from the school of nursing, but the University of Colorado does offer nurse/practitioner programs in adult care, and these are focusing on care of the arthritis patient as a part of the content. The University of Colorado does offer specialization at the master's level in care of the arthritis patient, although, again, in terms of the eminence of the disease having kind of decreased, only two students have completed that program. I think there's lots to be gained from the kind of publicity that's generated. Diseases that get popular attention from the press get more attention in medical and nursing centers.

VOICE: May I just venture the suggestion--you've made clear that you're not the person to whom I should make it--but where there has been experience with such efforts, I believe it could be a great help to the Commission if we had some record of this. So, if there is anyone in the audience who could follow through on this, we'd be very pleased to receive any brochure or any descriptive material of the sort of experience that you've had.

ENGLEMAN: Thank you, Miss Elliott. Now, I'll call on Dr. Steigerwald.

TESTIMONY OF  
JAMES C. STEIGERWALD, M.D.  
DIRECTOR  
ARTHRITIS LABORATORIES  
UNIVERSITY OF COLORADO MEDICAL CENTER

STEIGERWALD: My name is James Steigerwald. I am a rheumatologist and, at present, Director of the Arthritis Laboratories at the University of Colorado Medical Center in Denver, Colorado. I would like to speak to you today on two points: (1) the need for more treatment facilities for all arthritic patients, but especially for those who cannot afford private care facilities. During the past five years (from 1969-1974), I have had the opportunity to work as the rheumatologist for Denver Health and Hospitals, the health care system which provides care to all the people of



Denver. It became very apparent to me that in this system of health care geared to acute medical problems, there is essentially no opportunity for a comprehensive rehabilitative program for the arthritic, both because of the lack of chronic care facilities and insufficient personnel trained in this area. I would suggest, therefore, that in planning for arthritis treatment centers: (a) these centers must be available to all arthritics regardless of their ability to pay; (b) more personnel, including physicians, nurse practitioners, social workers, and other allied health workers, must be trained and then involved in the care of all. There is also a very definite need in Denver for these people to understand and speak Spanish as part of their job of providing comprehensive health care since this is the primary language of many of their patients.

My second point relates to the need for an increase in the number of researchers in the field of arthritis. Many significant advances have been made in the last decade, but the pieces of the puzzle are far from filled in. We need many more researchers, particularly at the basic science level, to try and unscramble more of the pieces. Unfortunately, what we are seeing is fewer people becoming involved in research. One of the main problems is lack of financial support to carry out research projects. The longer this problem exists, the harder it will be to resolve for we are developing a significant hiatus of competent young researchers to carry out the research.

With our current state of knowledge, we are unable to cure most of the arthritic patients. As the population continues to grow rapidly, we will be faced with the problem of more people with arthritis who require treatment but little new to offer them. I would suggest, therefore, that a significant portion of the funds available through the National Arthritis Act be made available for basic research in arthritis. This might best be done by grants directly to arthritis units (and not to individuals) which designate that a basic research program is an integral part of each unit so that those units that already have such a program may build on it, and those without must begin as soon as possible to develop such a program. In the long run, this is the only way the problem of arthritis will be overcome.

ENGLEMAN: Thank you, Dr. Steigerwald. Dr. Batchelor.

BATCHELOR: Might I ask Dr. Steigerwald whether he could build a bridge, perhaps, between some of his observations and those of Dr. Harry Ward, a moment ago. He's had experience here in Denver. The expectation is that so large a problem as patient care, regardless of means, is likely to receive support from multiple sources, rather than from a single grant. Have you, in fact, in your concern to provide this care here in Denver, have you had any experience that would indicate how this is likely to come about, or, have you had any experience with the new legislative thrust, for example, that comes with the Health Planning and Resources Act that was signed into law the same day as the Arthritis Act?

STEIGERWALD: I have not had any personal experience with actually getting this problem solved in the sense of taking the patients (INAUDIBLE) avail themselves of the private care facilities and actually get into a system where they can be maintained, or get into a program of



long-term care. I'm not sure that this is necessarily going to come out of this Act, but I do think that it has to be stated, sooner or later, if you are developing health care arthritis units, that this does have to be available to all our population and not just for those that can pay for it through their insurance or that have the private resources to do it. This, as I say, is probably into a different area, maybe a national health insurance or something of this sort, but I feel very strongly that it has to be incorporated that the funds are available for all.

VOICE: Dr. Steigerwald, I would just like to more or less echo one of the comments that you made, rather than ask a specific question--and that is the need for trained investigators in research. The ultimate provision of improved care methods is based on new knowledge obtained through research. And if we don't have the people properly trained and educated in those special techniques, then the product is just not going to be produced. I think perhaps the audience ought to be aware that, at the moment, the authorization that is the legal basis for continuing training programs of this sort through the National Institutes of Health has run out, and new legislation to continue that is in process but it has not yet been completed. And, I think it is quite appropriate for expressions to be forwarded for the need for this legislation to be passed as rapidly as possible.

The second part of it, of course, is that I trust we will get these authorizations restored then it's a matter of funding for training, and that, too, is not in good health at the present time.

Although we have in the past made available substantial millions of dollars for arthritis research, nevertheless, I think we're all in agreement that for us to achieve the purposes and fulfill the hopes in this legislation, substantial increases in appropriations must be made.

And, let me just finish my little speech by making it clear, as I suspect the Chairman did before I came, that the dollar numbers that appear in the Arthritis Act are not actual dollars, they are only authorizations. That is, they are statements of the legal limits to which money can be appropriated, and it remains for the appropriations committees, at least for the Federal sources of funding, to actually vote the dollars in the appropriation bills for the various institutes and for the other Federal operating agencies.

CHAIRMAN: Now, Dr. Polley.

POLLEY: I asked Dr. Harry Ward about the Colorado physicians because I heard yesterday that every medical student at the University of Colorado has some exposure to rheumatology, and I'd like to ask Dr. Steigerwald, or Dr. Clayton, or anybody else who may wish to answer, whether the care of the rheumatic patients in Colorado, in their opinion, is any better or worse than any other place in the country, because it's certainly not true that most medical students in most medical schools are exposed to rheumatology.

STEIGERWALD: That's an extremely hard question to answer because my basis of knowing exactly what's going on in other places is not all that

concrete. I do feel that our students, and the health staff particularly, do get a very good basic understanding of the rheumatological type diseases, both through the medical or the rheumatology point of view, and from the orthopedic and physical medicine and the other allied health points of view. So, I would say that, although we will certainly try to keep improving, we think we are doing a fairly adequate job--when the physicians go out they can recognize rheumatoid arthritis or systemic lupus or other diseases, and if they don't specifically know how to care for them, they know what to do as far as taking care of the patients.

VOICE: I think we're fortunate in that we do have a number of highly trained people in the area, and somebody said we have a large number of trained rheumatologists remaining in Denver. The Arthritis Foundation in this area for many years has been very active in sending out speakers for lay groups and public forums throughout our chapter area of Colorado and Wyoming, and on each one of these trips, usually the team will put on a clinic for the doctors in the area.

In the last year, we've almost saturated some of them; we don't want to go back for a while. I think that it has been before them, and doctors in the area are aware of the things that are available and what they can do in their area, and we already have a functioning unit for a center concept when it is better developed.

ENGLEMAN: All right, thank you very much. And we'll call on the next group of witnesses: Dr. Robert Godfrey, Dr. Kenneth Platt, Herbert Kaplan, Dr. Leidholt, and Mrs. Brofman. Dr. Godfrey.

SUBMITTED STATEMENT OF  
ROBERT G. GODFREY, M.D.  
DIRECTOR  
KANSAS REGIONAL MEDICAL PROGRAM  
ARTHRITIS PROJECT

I. Current Status

A. Personnel

1. Kansas University Medical Center, Kansas City, Kansas

\*a. Department of Medicine, Division of Allergy, Clinical Immunology and Rheumatology<sup>13</sup>

1. Daniel Stechschulte, M.D., Director
2. Herbert Lindsley, M.D., Rheumatologist
3. Nabih Abdou, M.D., Immunologist
4. Robert Godfrey, M.D., Rheumatologist (one-half time)

\*Fellows and research personnel not included.

14Rheumatology developed from one 1/8-time rheumatologist in past 3 years.

b. Pediatrics

1. Carol Lindsley, M.D., Pediatric Rheumatologist

c. Orthopedics

1. Frederick Reckling, M.D., Head

d. Rehabilitation Medicine

1. John Redford, M.D., Chairman
2. Charles Kelly, M.D., Consultant in Rheumatology

e. Ophthalmology

1. William Godfrey, M.D., Consultant in Rheumatology

f. Regional Medical Program Arthritis Project (See Appendix A)

1. Robert G. Godfrey, Director
2. Daniel Stechschulte, Director, Kansas City IEU (KUMC)
3. Virginia Wulf, RN-S, Nurse-Specialist, Kansas City IEU (KUMC)

2. KUMC - Wichita Branch

3. Kansas City, Missouri, VA Hospital (See Section II)

a. Medical Service, Arthritis Section

1. Robert G. Godfrey, M.D., Chief (one-half time)

4. Regional Medical Program Arthritis Project (Other than KUMC) (Appendix A)

a. Topeka IEU

1. Raymond Lumb, M.D., Director
2. Geneva Pantton, RN-S, Nurse-Specialist

b. Salina IEU



1. E. Dean Bray, M.D., Director
2. Loretta Kreie, RN-S, Nurse-Specialist
- c. Wichita IEU (WSU Branch KUMC)
  1. Frederick Wolfe, M.D., Director
  2. Marjorie Wilber, RN-S, Nurse-Specialist
5. Other Kansas physicians with 1-3 month segmental fellowship training in Clinical Rheumatology at KUMC-KCVAH (See Appendix B) and/or ARA members.
  - a. C. C. Conrad, M.D., Dodge City, Kansas
  - b. Richard Uhlig, D.O., Herrington, Kansas
  - c. Robert Fowler, M.D., Wichita, Kansas
  - d. Angelina Gabatin, M.D., Wichita, Kansas
  - e. John Lynch, M.D., Topeka, Kansas
  - f. Harry Wisner, M.D., Wichita, Kansas
  - g. Robert Easterly, M.D., Leawood, Kansas
  - h. Philip Baker, M.D., Topeka, Kansas
  - i. Dennis Finley, M.D., Wichita, Kansas
  - j. Royal Barker, M.D., Council Grove, Kansas
6. Kansas City, Missouri, physicians specializing or with training in rheumatology (ARA members)
  - a. Alfred Biggs, M.D.
  - b. John Layle, M.D.
  - c. John Wells, M.D.
  - d. Wm. F. Benson, M.D.
  - e. Charles Cooper, M.D.
  - f. M. L. Glazer, M.D.
  - g. William Goodson, M.D.
  - h. J. O. Osborne, M.D.
7. University of Missouri at Kansas City, School of Medicine

- a. Consultation Service - John Layle, M.D.
- b. Lectures - John Layle, M.D., and Robert Godfrey, M.D.
- B. Organizations
  - 1. Kansas Chapter, Arthritis Foundation, Wichita, Kansas
  - 2. Kansas City Chapter, Arthritis Foundation, Kansas City, Missouri
- C. Programs and Projects
  - 1. Clinical
    - a. KUMC-KCVAH: Kansas City
      - 1) Division ACIR (Appendix C)
        - a) Clinical Fellowship (2 year) - 1
        - b) Clinical segmental fellowship: 3, one-month fellowships/year for practicing Kansas physicians. Sponsored by Kansas Chapter Arthritis Foundation. (See Appendix B)
        - c) University Arthritis Clinic (H. B. Lindsley, Director)
          - (1) Includes fellows, residents, students, nurse-specialist, physiatrist, OT, PT, division and volunteer staff. (1/2 day/week)
        - d) AOP (Arthritis-Orthopedics-PM&R) combined clinic (1/2 day/month). (Drs. Reckling, Kelly, Lynch, Godfrey)
        - e) VA Arthritis Clinic (Dr. Godfrey) (1/2 day/week) and arthritis nurse-practitioner clinic (two 1/2 day/week)
        - f) Institutional and non-institutional educational activities
      - 2) Regional Medical Program Arthritis Centers Project (1974-1976) (See Appendix A)
        - a) Center, KUMC
        - b) Information and Evaluation Units (IEU's)
          - (1) Kansas City (KUMC)

- (2) Topeka
- (3) Salina
- (4) Wichita (WSU)
- 3) Wichita (WSU Branch KUMC), housestaff and student training (Fredrick Wolfe, M.D.) See Appendix E.
- 4) Kansas City Chapter Arthritis Foundation (Missouri)
  - a) Arthritis diagnostic and screening clinic

2. Research

a. KUMC-KCVAH: Kansas City

- 1) Division of Allergy, Clinical Immunology and Rheumatology
  - a) Stechschulte
  - b) Lindsley
  - c) Abdou
  - d) Godfrey
- 2) Orthopedics
  - a) Reckling
  - b) Asher
- 3) Rehabilitation Medicine
  - a) Redford, Kelly: Assessment and Evaluation of Function in Rheumatic Diseases.
- 4) Ophthalmology
  - a) William Godfrey - Ophthalmologic Manifestations of Rheumatic Diseases

b. KUMC - Wichita State University Branch

- 1) Frederick Wolfe, M.D. - See Appendix E

c. Kansas Chapter Arthritis Foundation

- 1) Supports four \$2500 research grants/ year



3. Public and Professional Education

- a. Kansas and Kansas City Chapters of Arthritis Foundation
  - 1) The Kansas Chapter provides essentially all formal lay and professional education in Kansas outside the Kansas City metropolitan area.
- b. Arthritis Project IEU's and Personnel
- c. KUMC-KCVAH (Kansas City): Primarily inter and intra-institutional plus participation in Postgraduate Medical Education Department programs and participation in Kansas Chapter Arthritis Foundation Professional Education programs. Also conduct the segmental rheumatology fellowship program sponsored by the Kansas Chapter. (See Appendix E)

II. Coordination with Local, Regional, and National VA Resources

A. Local

- 1. The Kansas City VA Hospital, while in Missouri, affiliated with KUMC.
  - a. Arthritis resources
    - 1) Rheumatologist (1/2 time)
    - 2) Arthritis Nurse-practitioner (See Appendix F)
    - 3) Rehabilitation Medical Service (no physiatrist)
    - 4) Orthopedic surgery service (non KU affiliated )
  - b. Potential
    - 1) A 15-20 bed regional VA Arthritis Treatment Center was planned and approved locally in 1971 but funding could not be obtained.
      - a) A similar Center could still be established at this hospital.
        - (1) The development of such VA Centers is now being considered actively by VA central office (See Appendix G)
    - 2) A regional VA Center at KCVAH could be coordinated RDU in the Kansas City metropolitan area with indigitating personnel and resources for optimal utilization in the overall local and national plan

for arthritis patient care, education and research.

### III. Summary of Resources, Problems and Needs

- A. Dispite a great increase in personnel, programs, facilities and resources in the past five to ten years, there is still no coordinated and cohesive application of arthritis care, education or research in Kansas or the Kansas City metropolitan area. Care, education and research are severely limited by the lack of funds, shortage of trained physicians and the underutilization of Allied Health Personnel.

#### 1. Patient care

- a. Except for Kansas City, Topeka, and Wichita, where trained rheumatologists, or rheumatologic orthopedic surgeons are located; and Salina, Dodge City, Herrington, Council Grove, and Wichita where there are physicians with 1-3 months of training in the segmental rheumatology fellowship program; the remainder of the State is virtually without physicians with special training or interest in arthritis. Prior to 1974 there were no full-time, formally trained rheumatologists in the entire State of Kansas. Even now, many arthritis patients must travel long distances or even leave the State to obtain more than minimal care.

- 1) Present rheumatologists and one 3-month segmental fellow now serve as directors of the arthritis nurse-specialist staffed information and Evaluation Units of the Kansas Arthritis Centers Project in Kansas City, Topeka, Salina, and Wichita.

- a) These units have demonstrated the ability of these trained arthritis nurse-specialists to perform a large variety of services for local arthritis patients and their physicians that were not formerly available. (See Appendix A.) Funding of this project expires July 1, 1976.

- 2. Present arthritis education and research, despite growth and great potential, suffer similarly from lack of funds and coordination.

- B. To meet the needs for arthritis care, education and research in Kansas and the Kansas City metropolitan area, present accomplishments need to be maintained, areas of strength exploited and expanded, and areas of weakness bolstered. To achieve this many steps should be taken, some of which are itemized below as recommendations. The recommendations reflect not only my own views, but hopefully also the views of other

physicians, organizations and institutions in Kansas and the Kansas City area whose advice, comments and criticisms I solicited prior to the final preparation of this testimony. (See Appendix H)

1. Establishment of an Arthritis Center and Rheumatic Disease Unit (RDU) in the Kansas City metropolitan area utilizing existing resources but with expanded facilities and personnel would seem the most effective way to meet more adequately the needs in Kansas and the Kansas City metropolitan area for this type of coordinated application against the rheumatic diseases.
  - a. To utilize existing facilities and resources most effectively this center should probably be located in or at the Kansas University Medical Center in Kansas City, Kansas (KUMC-KC).
    - 1) Because KUMC-KC will be a part of the Kansas City Metropolitan Health Service Area (MHSA), the KUMC-Wichita State University branch should be heavily represented in the overall development and funding of any Arthritis Center and Rheumatic Disease Unit program; since the WSU Branch will be directly responsible to many (if not most) Health Service Areas in the State of Kansas.
    - 2) For the same reason, any KUMC-KC Arthritis Center Program must also collaborate closely and interdependently with personnel, organizations and institutions on the Missouri side of the KC-MHSA including:
      - a) The Kansas City Chapter of the Arthritis Foundation
      - b) The Kansas City Rehabilitation Institute
      - c) The University of Missouri School of Medicine in Kansas City
      - d) The Kansas City Veterans Administration Hospital
      - e) Local private hospitals and physicians
  - b. The KUMC (at Kansas City and Wichita) Division of Allergy, Clinical Immunology and Rheumatology should be expanded in personnel and facilities to permit adequate staffing and operation of an Arthritis Center Program to provide exemplary arthritis patient care, education and research.



- 1) Develop in-patient facilities for both acute and intermediate patient care.
  - 2) Expand out-patient facilities to permit full-time, daily arthritis clinics.
  - 3) Expand in-service (one month segmental fellowships) physician training from 3 to 24 physicians per year.
    - a) Include KC-MHSA as well as other Kansas physicians.
  - 4) Expand Allied Health Professional training.
    - a) Arthritis Nurse-Practitioners
    - b) Arthritis Nurse-Specialists
    - c) OT-PT trainees
    - d) Social Service, vocational counseling, etc.
  - 5) Develop outreach services and training
    - a) Expand existing Kansas Arthritis Centers Project Information and Evaluation Units (IEU's) to become satellite Arthritis Treatment and Screening Centers by staffing each unit with a full-time (or several part-time) physician(s) trained in rheumatology
      - (1) Develop new IEU's (or mobile units) for smaller towns distant from the Kansas City, Wichita or satellite centers.
    - b) Develop arthritis center teams to visit remote communities and/or hospitals for demonstrations, patient care and teaching.
  - 6) Expand standard data collection for ARAMIS link-up.
- c. The KUMC-KC Center should utilize all KC-MHSA personnel, facilities, organizations, and institutions involved in arthritis patient care, education or research; and, at the same time, support and coordinate with these others for maximum efficiency and utilization of Center funds, resources and services.
- 1) The KUMC-WSU Branch should similarly utilize and support arthritis-related personnel of organizations and facilities Kansas. It should

closely coordinate its efforts with those of the KUMC-KC Center to permit exchange and sharing of resources for patient care, education, and research.

TESTIMONY OF  
ROBERT G. GODFREY, M.D.

GODFREY: Thank you, Dr. Engleman and the Commission. My name is Dr. Robert Godfrey. I'm from Kansas City, and I'm here to speak about arthritis in the Kansas City and Kansas area. I'm with the University of Kansas at Kansas City, Kansas, and with the Veterans Administration Hospital in Kansas City, Missouri. In addition, I'm a member of the chapter of the Arthritis Foundation in both Kansas and the Kansas City area.

I think, hopefully, that the written statement which I have presented here today is a composite, not only of my own views, but of those of many individuals in the State with whom I worked in the last 12 years while I've been practicing rheumatology in Kansas City, and concerned physicians, individuals, organizations in the metropolitan Kansas City area and throughout the State of Kansas. In addition, I wrote a memorandum specifically asking for advice and suggestions pertaining to my testimony before this Commission.

As Dr. Ward said earlier, the concept of arthritis centers is going to be a difficult one. The balance between research, education, and patient care will also be a difficult one. I think I would certainly agree with him that our emphasis should be towards the particular areas, specific needs, and toward a particular project and things that already have going the utilization of resources that are already available.

I think that Kansas City and the Kansas area have many (INAUDIBLE) activities that are listed in the outline I gave you and would have much in common with most other areas.

Like everyone else, I suppose, we have too little of everything to get the job done really well. But, on the other hand, we do have some particular strengths which should be exploited and developed in any arthritis program for centers in our area. I'd only like to mention a few of these. For example, I think one of our strongest points is that at the University Medical Center in Kansas City, we've evolved an especially strong interdepartmental rheumatology team (INAUDIBLE) rehabilitation medicine, orthopedic surgery, and the nursing school.

We hold combined clinics; exchange residency fellows; and collaborate medical student, allied health professional, and postgraduate medical teaching programs.

In 1973, Kansas City General Hospital was selected to establish the first real arthritis nurse/practitioner clinic. The details of this particular pilot project are in appendix "F" of the materials that I gave you. The success, over the years, of this pilot project and the experience that we gained from it, led directly to the three-and-a-half-

month formal arthritis nurse-specialist grade training program, which we developed for the four nurse specialists who now staff and operate our information and evaluation units as part of the Kansas Arthritis Center's Regional Medical Program Project.

These units are located in Kansas City, Wichita, Topeka, and Salina. In these, as we call them, IEU's, under the indirect supervision of the local rheumatologist, these nurse specialists provide information to the public and patients about arthritis and, on request, assist local physicians with their evaluation and management of their individual patients. Appendix "A" contains the details of this particular program, along with some early evaluative data.

Additionally, the Kansas chapter of the Arthritis Foundation sponsors three one-month segmental fellowships per year which bring practicing physicians from the State of Kansas to come to Kansas City for a month of intensive on-the-job training in medical/clinical rheumatology. The details of this project are in appendix "B" in the outline I've given you.

It's been interesting that upon their return to private practice, these physicians provide greatly improved care to their own patients and have often become the local expert in arthritis for several counties, as well as a readily accessible informal resource for rheumatologic advice to their fellow physicians in their areas.

I think that programs such as these are especially vital in Kansas, where the main medical center is in Kansas City in the extreme northeast corner of the state, and even our Wichita branch of the University Medical School is hundreds of miles from our western counties. Kansas has several counties with no physicians at all, and we believe it's crucial that physicians who are willing to stay be given every opportunity to improve their skills in treating arthritis and to be provided more readily accessible rheumatologic (INAUDIBLE) these services and skilled allied health management assistance.

Without the implementation of the health service area legislation, the KU medical center will be further cut off from the State, since the medical center will fall into the Kansas City metropolitan health service area. This is such a bag of worms that nobody quite understands the eventual outcome. But it seems clear that the medical center in Kansas City will have to expand its cooperation with the Missouri side of the city, while at the same time making an effort to fulfill its responsibilities and obligations to the entire State of Kansas.

I believe this can be done, but even so, it vastly increases the importance of the KUMC branch in Wichita, which conceivably could be called upon to provide health services to all of Kansas except the three counties in the Kansas City metropolitan area.

There is grave concern throughout Kansas that I should not fail to emphasize the necessity of the KUMC Wichita University branch being a strong, active, and financially supported program in the development of an overall arthritis center's program for Kansas and Kansas City.



I was going to speak about the VA program (this is noted in appendix "G".) This is actually not necessary since in talking to Dr. (INAUDIBLE) in the central office who is now the program director for immunology and rheumatology, I realize that there are VA members sitting on this Commission, and, therefore, you have access to their programs and what is going on.

In any case, the only thing I would like to emphasize in that regard is that there is an enormous amount of rheumatologic expertise available within the VA system. And, fully utilized and coordinated with public and private efforts, I believe it could greatly enhance the impact of the eventual implementation of the Act.

Those of us in Kansas City and Kansas feel that the implementation of this Act must not only show a thoughtful balance of research, education, and patient care programs, but also be flexible in its ability to serve the special needs of individual areas and regions and to utilize fully the private and public resources and special skills and programs which already exist in each area.

One last comment would be that often people don't think in terms of health care delivery as being a valid and very important form of research, but we certainly consider this to be very important to us in an area where we are very much understaffed with physicians and even allied health personnel well trained in rheumatology.

Thank you.

ENGLEMAN: Thank you.

SHIELDS: I would like to just ask one question; it's one that we've asked earlier and that is--of course, there are limited funds--would it be your feeling that we should put these funds into a few centers or into many centers?

GODFREY: Well, generally speaking, I think I would be inclined to favor at least a comprehensive center in each region. Then from that point on, I would suggest that each individual medical school could be responsible for cooperating with the major center, or actually be a major center.

But then, in addition to this, for places like Kansas we need outreach programs with satellite screening. Diagnostic and, hopefully, treatment centers, such as these information evaluation units I mentioned to you, could be expanded by the addition of a trained physician to perform that sort of diagnostic and screening service, again, relating back to either the regional or the main arthritis center.

ENGLEMAN: Okay, any other question?

VOICE: I'd like to ask Dr. Godfrey, in view of your interest in developing the outreach and utilizing all the resources in your region, whether you've had any experience along the lines that are spelled out in the new law, the Health Planning Resources Act, the establishment of the

so-called health systems agency. Has there been any progress in this area in your part of the country. You've been so active in these developments, certainly if you've had any experience along these lines, too, I for one would like to hear something about it.

GODFREY: Well, all I can say is that no one has really had any experience in development of these things. We don't know how they're going to work. We have some grave concerns about taking our only medical school and putting it in a metropolitan area that can conceivably be dominated by Missouri, out of the State. Yes, Kansas people are very much concerned about this.

I don't know exactly how it's going to work. I feel that, as I said, it's going to be very important that in these health service areas we try to develop resources to serve that area specifically. It just so happens that one of our information evaluation units falls in each one of the other Kansas health service areas that have been designated, including one in Kansas City.

VOICE: Thank you.

ENGLEMAN: Dr. Polley, then I'm afraid we must move ahead.

POLLEY: All right. Am I correct in assuming that this is an outline of some more detailed material that you've submitted?

GODFREY: That, Dr. Polley, is a--not exactly an abstract. It has the complete outline of the information of my basic presentation, but only the front pages of the appendices, which are included in the master over there, which I'd like to submit, and there's testimony in a more complete form.

POLLEY: And there's more detail in there about the evaluation?

GODFREY: Yes, sir.

POLLEY: Yes, that's what I'm after.

GODFREY: If you'll look at the appendix pages, it shows what these actually include.

POLLEY: Thank you very much, appreciate it.

ENGLEMAN: Now. Dr. Platt, please.

TESTIMONY OF  
KENNETH PLATT, M.D.  
MEDICAL DIRECTOR  
COLORADO FOUNDATION FOR MEDICAL CARE

PLATT: Well, Mr. Fields and members of the Commission, I just heard you mention something I think all of us are becoming increasingly aware of, and that is that you are responsible for limited funds. I think the entire country recognizes the fact that funds are limited and becoming increasingly limited by a lot of varying pressures.

If I bring any area of expertise to the Commission today, it's perhaps in the field of utilization and quality assurance of the things you're responsible for, and which the Federal Government and state governments are responsible for.

Basically, I am the Medical Director of the Colorado Foundation for Medical Care, which is the official professional standards review organization for the State of Colorado. We have been responsible and are now entering our third year as the formal utilization review and quality assurance mechanism for the Federal programs under Title XI of the Public Law 92-603.

We are operating at the present time in all of the acute care hospitals in the State of Colorado, as well as in the ambulatory sector for the Department of Social Services, and monitoring the care given some 95,000 to 100,000 private-pay patients in the State of Colorado.

Now, you're concerned with the expenditure of funds for a specific disease entity, for both research and direct patient care. And I am responsible for monitoring the quality and utilization of the care rendered the patients in the State of Colorado, in increasing numbers and increasing complexity.

I might say that the profession in the State is now both willing and, hopefully, able to guarantee to you, the Commission, and to the patients who will benefit from your program that the utilization of those funds and the quality of care rendered in the utilization of those funds will be, we believe, of the highest order.

Now, this is a new program, as I'm sure you're aware. The National Health Systems Agencies was just brought up--that's a new program; we're all feeling our way along in these things, trying to decide how one, indeed, monitors utilization and how one measures quality. And, basically, what role does the PSRO play in the health systems agencies, and how do these things dovetail?

As we see it, PSRO will be responsible for a great deal of the data gathering upon which the health systems agencies will make their ultimate utilization review, or the structural review, the facilities planning, and so on, that they must indeed be responsible for.

I can say that after three years--going into the third year--of doing this in the acute care institutions and over three years in the ambulatory



sector, there certainly has been a lot learned, and there certainly is some merit in setting aside finally in the third biggest industry in the country, some form of quality assurance and utilization review mechanism.

I'm not certain that what we're doing will be the ultimate Cadillac of this sort of program, but it certainly has gone beyond the Model T. I hope it's not an Edsel, but only time will tell. I can guarantee you this, that as we experiment and as our results are forwarded to the Federal Government and to the state departments of social services, we are open to suggestions. We're perfectly willing to amend our ways if they're proven, indeed, to be improper, but the physician community, given the responsibility that it has been given, is not only willing but capable of doing this type of review.

I think there were some quizzical glances--at the time this all was passed--in some of the hierarchy of our United States Congress as to whether or not we would indeed turn out to be the fox guarding the hen house in our approach to utilization review and quality assurance.

I can now certainly attest to the fact that that is not true and that we have the facts and figures to prove it. So, once again, speaking for the doctors in the State of Colorado and for the other providers--the nurses, the psychologists, the podiatrists, and all those groups that are participating--the professions are capable of guaranteeing you that we will indeed be extremely responsible for patient care; under your Commission and under the funds entrusted to you, to the extent of our ability, we will help you in monitoring both utilization and the quality of care rendered in those centers.

A much more formal presentation could be made, and a lot of information will be sent to you for study, I hope for help. If there are any questions about it or any comments, I'd be happy to answer them.

ENGLEMAN: All right, thank you. Do we have any--Dr. Polley.

POLLEY: Dr. Platt, I'd like to ask if you are in any position to answer my previous question, whether arthritic patients receive better, or average, or worse care in Colorado than they do in other states where the medical profession, presumably, is less well trained?

PLATT: That is indeed a difficult question. Let me say that I've had an opportunity to travel around the country, and my impression is that Colorado does indeed enjoy a high standard of care in many sectors, particularly in the arthritic area, and that is due, in large part, to people like Dr. Smith, and so on, at the medical school.

In competing with other states, I don't profess to have that kind of background. I would hesitate to answer that affirmatively or negatively. Let me just say this, that from what I've observed, it's a very high quality in the State of Colorado.

POLLEY: Thank you.

ENGLEMAN: Go ahead.

KAPLAN: Since Dr. Polley has asked that question several times, and since my time will be limited, I'd like to use someone else's time period to answer that question.

As the result of Dr. Charlie Smith's active clinic teaching program at the University of Colorado for the past 20-plus years, rheumatology care in Colorado is superior; in the City of Denver and environs there are 12 or 13 men with expertise in rheumatology. This, I think, compares quite favorably with any other similar population area in the country.

From my friends around the country, I know cities such as San Antonio until recently--I hope I'm not offending anybody from Texas--had no clinical rheumatologist, and when I refer patients leaving Denver to other areas, I have trouble finding adequately trained rheumatologists in cities the size of Denver elsewhere in the country that I can refer my patients to.

So, in answer to that question, the rheumatology care in Denver is superior because of the active training program carried on by Dr. Smith. I should mention that I think all but one of these rheumatologists was trained by Dr. Smith and stayed in the area. Skiing may have helped a little bit, but the fact remains that the care here is better because of active teaching in this area.

POLLEY: Thank you. I was going to ask Dr. Kaplan anyway, so I appreciate his answer.

VOICE: I'd like to just steal a few seconds here also because I took three years of my training here in Colorado under Dr. Smith and then moved to Kansas City. So, I can say certainly for a fact that Colorado is blessed with an extremely superior system of care, research, and educational programs in rheumatology. Certainly much more so than our area which is just now developing in somewhat along the lines, as you might imagine, as the things that I learned here.

ENGLEMAN: Thank you. I notice Dr. Smith is standing down at our left. Dr. Smith, maybe you better take a bow.

SMITH: Thank you.

ENGLEMAN: I think we should move ahead. Are there any other questions? Dr. Kaplan, I believe it is your turn now, if you would pass the mike please.

TESTIMONY OF  
HERBERT KAPLAN, M.D.  
ATTENDING PHYSICIAN  
JOE AND BETTY ALPERT ARTHRITIS TREATMENT CENTER  
GENERAL ROSE HOSPITAL

KAPLAN: After almost one year of operation, our experience in the Joe and Betty Alpert Arthritis Treatment Center at General Rose Hospital attests to the value of the intensive multidiscipline approach to the patient with rheumatic disease. In this 22-bed unit, which is an integral part of a Denver community hospital, we have had many dramatic examples of the successful treatment of patients who otherwise would have, without this intensive approach, progressed to irreversible deformity. As a practicing rheumatologist who hospitalizes all of his patients in this unit, I have seen the value of this coordinated effort of physician, nurse, physical therapist, occupational therapist, social worker, and home visiting nurse. With this team my ability to control and, in some cases, cure rheumatic disease is multiplied many fold over that which would be possible in the traditional one-to-one doctor patient relationship.

Each patient in the unit is seen by this team, the members of which have expressed a definite interest in rheumatic disease, and who have had additional in-service training in the problems unique to the arthritic patient. The arthritis nurse specialist, with a master's degree in nursing, coordinates the program and is responsible for its educational aspects, utilizing videotapes, anatomic models, and library materials. The ward nurses, familiar with the proper use and mechanism of action of the various analgesic and anti-inflammatory drugs, also participate in patient education. They encourage patients to take medication on their own, as they will after hospital discharge, and on a schedule that will be more therapeutically effective and which will keep side effects to a minimum. The nurse also acts as an interval physical and occupational therapist to encourage performing activities learned in the Physical Medicine Department on the ward.

Aggressive physical therapy is almost invariably indicated in patients hospitalized in this unit, and again an interested and specially trained physical therapist is assigned to each patient, and treats him twice daily in a program aimed at restoring and maintaining function. No less important is the occupational therapist, whose emphasis tends to be on upper extremity function and in improving activities of daily living with joint protection techniques, assistive devices, and, when possible, home visits prior to discharge to better appreciate the individual problems to be encountered subsequent to discharge.

A social worker who has requested assignment to the Arthritis Treatment Unit interviews both the patient and family. After a goal-oriented conference with the attending physician early in the hospitalization, she initiates plans for the posthospital maintenance of the improvement achieved during the hospital stay. Without this assistance, adverse but possibly correctable social and economic factors have in the past wiped out whatever success was achieved during the hospitalization.



Weekly meetings of this entire team have been the keystone of this program. A representative from the Visiting Nurse Association sits in on the conference to assure continuation of the program at home. She arranges for follow-up home physical and occupational therapy, or the return to the hospital for periodic outpatient treatment when indicated. When indicated, family members attend these conferences, and in selected instances, patients return as outpatients to meet with the entire team for follow-up evaluation and "booster" meetings with team members as well as for the traditional physician evaluation.

In order to assure the continuation of this specialized care, adequately trained medical and allied health personnel are needed, both for our unit and for others like it. Until now, not only has there been a shortage of physicians trained in rheumatology, but there has been no specialized training at all for allied health personnel with a specific interest in this area of health care. With the all too common feeling that "there is no cure and nothing can be done for arthritis except take aspirin," physicians in training and their allied health personnel counterparts are "turned off" by rheumatic disease. The therapeutic triumphs achieved in our unit have stimulated an interest in rheumatic disease in the attending physicians in our hospital, in the intern and resident staff rotating through the unit, and in the allied health personnel that have witnessed this success.

A postgraduate program for both physicians and allied health personnel was sponsored by General Rose Hospital this past year, and the hospital has appropriated funds for the training of a Rheumatology Fellow and partially funded an Orthopedic-Rheumatology Fellow. However, a private hospital cannot continue to provide the funds to carry on an educational program of the magnitude necessary to train the large number of personnel for the programs described here. We hope that these funds will be made available to enable us to continue our program at General Rose Hospital and for others like it in other parts of the United States.

The unit has been a financial success (INAUDIBLE) we are unable to care for patients who do not have third party insurance. So, if you're looking for ways to spend money and for giving care to people who can't-- then let's talk about Blue Cross-Blue Shield, for example, and Medicare. This hospital is a private hospital. The unit has been self-sustaining up until now, but we have not had any beds for people who are unable to present the admitting office with an adequate insurance policy.

In conclusion, this unit has shown success in both patient care and education. I think we need more--we need more funds to continue this (INAUDIBLE) and I think that more should be established all over the country.

SUBMITTED BY  
PHYSICAL AND OCCUPATIONAL THERAPISTS  
AT GENERAL RCSE HCSPITAL  
(Attached to Dr. Kaplan's statement)

Funding is needed for education of allied health in the care of arthritis on a continuing-education basis, and graduate level. Treatment of the arthritic is a form of specialization for the allied health team, and the advanced knowledge is not provided on an undergraduate level. At the present time, experience is the main basis of our knowledge, and this is proving inadequate as we are becoming a teaching center and other allied health members are looking to us to provide imaginative and creative patient-care programs.

In addition, funds for clinical research are needed. We need to know if the current treatment methods are beneficial objectively as well as subjectively. Examples: What is the physiological effect of superficial heat applied to an inflamed joint? What is the effect of resistive exercise vs. isometric exercise vs. active ROM on an arthritic joint in the various stages of R.A.? Does splinting make a difference on joint deformityearly spinting vs. late splinting vs. no splinting? Is our patient education program making a difference - should it be done via local allied health or do arthritis centers need to send "specialists" out? So far, work has been done with outlying allied health, but is the information getting to the patient? These are but a few of the many areas that need to be explored by allied health and an attempt made to answer some of the questions. The private hospital is not in a position to provide funding for clinical research and education, therefore we must look for public funds to accomplish our goals of improving care for the arthritic patient.

ENGLEMAN: Any comment? Dr. Batchelor.

BATCHELOR: Dr. Kaplan, I'd like to pick up one point you made having to do with the follow-through of the patient in the community. Let me say by way of background that our deliberations have benefited very much by the expression of the point of view of the skeptic. And, the skeptic talking about centers has brought to our attention the concern that the centers are fine as long as the patient is there, but the problem of follow-through when the patient leaves is seen by many as a serious one. And, I wondered whether you would care to expand a little bit on what one might do other than send a nurse out to check and bring them back--bring them back to the entire team? How about the allegation that perhaps 90 percent of the arthritis care in the country must in the present and future be given by the nonexpert? How can we bridge this gap between the marvelous things you do in the center framework and what must go on afterward?

KAPLAN: One thing that I alluded to was using the center as a source of training for outlying physicians--this Friday two physicians from Jackson Hole, Wyoming, are coming down to learn a little bit about arthritis. When they get back to Jackson Hole, they will know a little bit--maybe two days' worth--of rheumatology, at least, but it's better

than what they have already. So, it's one way to expand, geographically, our efforts.

Number two, we do have (INAUDIBLE) such as arthritis nurse specialists, which are trained in our units to go out into the hinterlands and train nurses in the outlying areas (INAUDIBLE) in Colorado and Wyoming. So, the nurse who's trained in our unit goes out and trains nurses in the outlying areas who are then better able to give care to people who otherwise would not reach our centers.

CHAIRMAN: Thank you. I think we must proceed now to the next witness, Dr. John Leidholt.

TESTIMONY OF  
JOHN D. LEIDHOLT, M.D.  
PRESIDENT  
NATIONAL FOOTBALL LEAGUE PHYSICIANS' SOCIETY

LEIDHOLT: I would like to introduce myself. I am John D. Leidholt, M.D., of 2045 Franklin Street, Denver, Colorado. I have been involved as an orthopedic surgeon in both the treating and studying of sports injuries for most of my career. In addition, I have had the opportunity to work with and treat patients with various types of arthritis for 25 years. Since 1969 my colleagues and I have acted as team physicians for a professional football team, the Denver Broncos, and have also had the chance to treat patients with athletic injuries from high schools and colleges.

In addition to memberships in numerous orthopedic and arthritis organizations, I am presently acting as President of the National Football League Physicians' Society and am also a member of the American Orthopedic Society for Sports Medicine.

The purpose of this brief statement is to bring to your attention the needs of the athlete in respect to the frequent complication of traumatic arthritis that results directly from athletic injuries.

With regard to the interest of this Commission, I would list the present needs as follows, and I do not list these in regard to priority: (1) Data and clinical record collection on the types of injuries and resultant arthritis; (2) Clinical and laboratory studies on the etiology or cause of traumatic arthritis; (3) Education of the public, coaches, and physicians in early recognition of injuries; (4) Development of new techniques and materials, for both the care of acute injuries to prevent arthritis and the treatment of old injuries.

Let me present just a few figures to define the magnitude of the problem. I'll discuss football because it's a sport in which maximum exposure to injuries occurs. Recent studies reveal that there are approximately 1,200,000 high school and 70,000 college football players. It is estimated that there are an additional 200,000 boys playing in various other community agencies. It is estimated that between 50 to 80 percent of the high school football players sustain injuries. If applied



nationally, the present injury problem would represent between 200,000 and 4,000,000 injuries each fall. This figure would compare with the ones I obtained from the study of a Denver school facility. Of course, many of these are minor injuries. One estimate was that from football alone, in 1966, there were 45,000 knee operations. Dr. Nicholas in New York City estimates the national figure to be somewhere around 30,000 a year. There are thousands of other injuries in other sports and the exact numbers are unknown. In 1972 it was estimated that 180,000 skiers sustained injuries. How many trick knees and trick ankles result from these injuries? Rall studied 205 former University of Missouri football players, he found 51.2 percent had a history of knee injuries, and all but one had persistent symptoms. A smaller group of 44 showed 84 percent had X-ray evidence of traumatic arthritis.

In 1969, there were 97 injuries in the National Football League that required surgery. Seven of those were on the Bronco Football Team. Only two are still playing football.

Fortunately, rule changes and the alteration of footgear appear to be reducing the number of serious knee injuries at all levels. It has been our experience in Denver that the improvements reflect the intensive efforts of persons in all related fields. Energetic investigators in medicine, physiology, and physical education work for the common goal of protecting the athlete.

Let me now reemphasize a few of the important points.

Some excellent recent epidemiological studies regarding the incidence of sports injuries have been done, namely the Blyth report from North Carolina and Ellison's studies on ski injuries. But, to date, no long-term studies on the consequences of these injuries have been made. These studies are essential to understanding the overall problem. The possibilities of a study of the professional athlete through the NFL Players' Association has been considered.

There is more than ample clinical evidence that ligamentous injuries and the instability that results from them result in early degenerative arthritis. This is the crippling "trick knee." Experimental studies in dogs by John Marshall confirm this impression. Therefore, both biomechanical and histochemical studies on the injured joint, as well as experimental models, should provide us with information that would lead to the prevention or limitation of this common complication. New work with the use of artificial ligaments is in the earliest stages of development.

Of immediate importance is the education of the lay public and those in the coaching and teaching professions to the fact that early recognition of sports injuries and proper early care has the best chance to prevent traumatic arthritis. It is disheartening to see a young college athlete who has had an injury in high school which was not recognized. Not only is his college athletic career jeopardized, but he may well not even be able to continue along in recreational sports. Television educational specials, literature made available through numerous organizations, seminars and special courses for teachers and coaches have been most helpful in the past. More are still needed.

Regional sports medicine meetings and courses for family physicians have updated medical knowledge. More emphasis for these physicians is still needed because most of the high school athletes injured are first seen by their family physician. A program for providing high schools with trainers and team physicians has been recommended by myself and many others. I hasten to add that patient education, the education of the athlete and his family, is still the key part to any preventive medical program. This can best be done by the coaches themselves.

I have already mentioned the early experimental work with artificial plastic ligaments. All of the orthopedic skills and special methods to repair and replace injured joints that have and will be presented to you in your hearings obviously pertain to the injured or traumatic arthritis joint of the athlete. Efforts along this line not only help the young athlete today, but will provide him with the special care and needs in his future.

Let me thank you for this opportunity, and I will be happy to answer any questions. Thank you.

#### Bibliography

Blyth, C.: An Epidemiological Study of High School Football Injuries in North Carolina, 1968-1972, U.S. Public Health Service, Grant Number FOA00032-02.

Craig, Timothy: Comments in Sports Medicine, Department of Health Education, American Medical Association.

Allen, Muary A.: Air Force Football Injuries: A Statistical Study. JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 206:(5) 118-122, May 4, 1964.

American Medical Association, PROCEEDINGS OF THE SECOND NATIONAL CONFERENCE ON THE COMMITTEE OF THE MEDICAL ASPECTS OF SPORTS, Washington, D.C., November 27, 1960.

American Medical Association, PROCEEDINGS OF THE NATIONAL CONFERENCE ON HEAD PROTECTION FOR ATHLETES, Chicago, May 19, 1962. American School of Health Associations: A Manual for School Physicians. JOURNAL OF SCHOOL HEALTH, 37:395-399, October 1967.

Brashear, Robert G.: Basic Areas of Prevention of Sports Injuries. JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 171:1664-1665, November 21, 1969.

Competitive Sports and Their Hazards. STATISTICAL BULLETIN, METROPOLITAN LIFE INSURANCE COMPANY, 46:1-3, September 1965.

Featherstone, Donald F.: SPORTS INJURIES MANUAL FOR TRAINERS AND COACHES. London: Nicholas Kaye, Ltd., 1954.

Haddon, William; Ellison, Arthur E.; and Carroll, Robert E.: Skiing Injuries. PUBLIC HEALTH REPORTS, 77:(11), 1-17, November 1962.

Hirata, Isao, Jr.: The Henly Cleat and the Ivy League. JOURNAL OF THE AMERICAN COLLEGE HEALTH ASSOCIATION. 17:367-370, April 1969.

Hughston, Jack C.; Wately, George S.; and Dodelin, Richard A.: The Athlete and His Knees. SOUTHERN MEDICAL JOURNAL, 54:1372-1378.

Lloyd, Frank S.; Deaver, George G.; and Eastwood, Floyd R.: Safety in Athletics: The Prevention and Treatment of Athletic Injuries. Philadelphia: W. B. Saunders, Co., 1939.

McPhee, Harry R.: A Survey of Knee Injuries in Football. STUDENT MEDICINE, 10:422-429, April 1962.

Nettleton, John D.: Factors Associated with Major Knee Injuries in Varsity Football. 67TH PROCEEDINGS, ANNUAL ASSOCIATION MEETING, NATIONAL COLLEGE OF PHYSICAL EDUCATION FOR MEN, January 8-11, 1964.

Paul, W. D.: Standards for Protective Equipment. PROCEEDINGS OF THE SIXTH NATIONAL CONFERENCE ON THE MEDICAL ASPECTS OF SPORTS. American Medical Association, Miami Beach, November 29, 1964.

Rall, Kenneth; McElroy, Glen L.; and Keats, Theodore E.: A Study of Long-Term Effects of Football Injury to the Knee. MISSOURI MEDICINE, 61:435-438, June 1964.

Ryan, Allen J.: Organized Medicine and Athletics: The Role of the American Medical Association Committee on Injury in Sports. AMERICAN JOURNAL OF SURGERY, 98:325-327, September 1959.

Shaughnessy, Clark: The Football Coach and the Team Physician. JOURNAL OF THE AMERICAN COLLEGE HEALTH ASSOCIATION, 15:113-120, December 1966.

Stein, Lloyd: Prevention and Treatment of Knee Injuries in Athletics. MINNESOTA MEDICINE, 49:1277-1279, August 1966.

Thorndike, Augustus: ATHLETIC INJURY PREVENTION, DIAGNOSIS AND TREATMENT, Fifth Edition. Philadelphia: Lea and Febiger Publishers, 1962.

ENGLEMAN: Thank you very much for a very important discussion which is directed actually to an area of the Arthritis Act which we have not talked about very much. Is there any organized effort by the sports people in the football and baseball associations and others to support research in this area?

LEIDHOLT: No, there really has not been. There has been an effort through the consumers' products committees in (inaudible) to study football equipment, and that has been a financially supported effort. The epidemiological studies have been assisted through Public Health grants. There are numerous groups, both in orthopedics and through the AMA, that are studying sports injuries.



ENGLEMAN: But the sports industry itself is not supporting any such investigations?

LEIDHOLT: No.

ENGLEMAN: It seems to me that there is such a great loss of funds to the sports industry that this would be an area that would be just wide open to support by the sports people.

LEIDHOLT: Yes. I think some of those funds would be forthcoming if they requested them.

ENGLEMAN: Yes.

VOICE: I have a comment and a question. As a football fan, I hope you're not advocating labeling it, "It's dangerous to your health."

My question is to the gentleman at the table now, and it relates to pain. Here it reads that you're associated with it and working with it, and so forth. Is there any research specifically associated with the pain in arthritis, or in the traumatic injuries in particular, that you know of?

LEIDHOLT: I don't know of any special projects studying the kind of pain related to arthritis. Of course, there are many efforts in local treatment, (inaudible) continuous nerve stimulation to control the pain, and those are ongoing projects.

POLLEY: A few years ago, in one of the professional football programs, there was an article by one of the Minnesota Vikings entitled, "Even If I Get Arthritis, It's Worth It." It caught my eye, particularly because there wasn't any question about whether he was going to get arthritis. Secondly, I'd like to write him in about 15 years and see if he still feels the same way.

LEIDHOLT: He may not.

POLLEY: That's what I think. I think most of the patients here would agree with that, but I merely make that comment to highlight the need to address this aspect of arthritis.

VOICE: In the same vein, I have a public confession to make, Dr. Leidholt. When I was listening to your testimony, I was thinking to myself, "Well, this is a rather specialized area for the athlete," and suddenly my knee twinged. I recalled that I'm not an athlete, and, by gosh, I have a twisted knee from one afternoon on the ski slopes; it's just been bugging me year in and year out. I wonder how many hundreds of thousands of other people have been playing sandlot baseball, or something like that, and have hurt themselves. You're talking about the same thing here.

LEIDHOLT: Exactly.

ENGLEMAN: Thank you very much. No doubt you'll be hearing from some of us. We'll now call on Teresa Brofman.

TESTIMONY OF  
TERESA BROFMAN, R.N.  
DIRECTOR OF NURSING AND HEALTH PROGRAMS  
STATE OF COLORADO CHAPTER, AMERICAN RED CROSS

BROFMAN: Members of the Commission: I am Theresa Brofman, Director of Nursing and Health Programs (inaudible) of the American Red Cross (inaudible) the State of Colorado--and part of our responsibility is being requested to teach home nursing. We teach this course to many different types of people: home health aides, convalescent day care personnel, home ec. teachers, nurses' aides, homemakers, interested citizens, high school students, and college students. Part of our course includes the rehabilitation of the chronically ill person. They do learn, let's say in a limited fashion, about arthritis, what it does to the patient, and what basic nursing skills will be applied, (inaudible) will help this person.

Our classes are continually being revised. Centers such as those being suggested at the local level could be our resource for keeping our volunteer and staff nurse instructors current and competent. Nevertheless, I feel that we do reach many, many people that are reached in no other way.

I want to echo Miss Elliott's comment on the rank of education in the schools of nursing in the field of arthritis. I have talked to many of the students recently, and they say that they get a very negative attitude towards it, and it is really mentioned rather casually to them. Let's say the (inaudible) would be the exception. Certainly, centers such as those being suggested today would be a place for not only the basic education of nursing students, but also for the graduate student, continuing education--which has been mentioned--and research to show how nursing intervention can help with the arthritic patient.

Also, we have heard outreach mentioned many, many times. Nurses throughout this area, which, as you know, is more rural than it is urban, could benefit from the use of modern communication so that they could be brought up to date and current in what is going on in the field of nursing and the arthritic patient. We feel that it isn't necessary always to bring people into the large medical center; that with modern communication we could help the nurse out in other areas become much more skillful.

Also, I think we're all aware that the gains in knowledge are not put into practice very, very quickly. Having comprehensive centers throughout the country with outreach capacity would make it possible to have practice and knowledge more closely together. Also, these centers could help the nurse who, in many instances, is one of the prime care-givers. She should call upon other members of the helping profession; she should call on the nutritionist, the social worker, the psychologist, and so on.

Rose Hospital, with its existing programs and such people as Dr. Smith and a relationship with the Colcrado Medical Center, certainly is an

ideal location for research into all the different facets of cause, prevention, diagnosis, and treatment, and the dissemination of this information throughout the area of the Rocky Mountain region. There is a need, and it's frequently expressed by nurses, for a resource that they may go to in regard to equipment. We're all well aware of the quackery to which the victim of arthritis is subjected. Nurses counseling patients about equipment need to know where they may go to get accurate information about what is appropriate and adequate equipment.

I'd like to share with you some of the information that I just received from the Visiting Nurse Service. I have been very active with this organization for over 20 years. In the month of September they had 700 referrals. One hundred of those referrals were, for either the primary or the secondary reason, for arthritis equally divided between osteo and rheumatoid. They have been researching their records for the past two years and have found that over half of their patients are on some medication for arthritis. So, this is a caseload which is rather significant; over half of their patients are on some medication for arthritis. There again it was indicated through their records that it was pretty evenly divided between osteo and rheumatoid.

I'd like to share with you in closing an incident that a young Public Health Nurse from this staff of the Visiting Nurse Service shared with me. I asked her how she felt an arthritis center could help her in her practice. She said her greatest need was in-service education (inaudible) of such patients and the depression that they experience. This is a graduate of a five-year baccalaureate program who has counseled in the more difficult areas such as child abuse, rape, mental health follow-up. She related that she was recently sent to counsel with a family in which a suicide had taken place. She learned that the person had committed suicide because of arthritis. This young nurse is calling for help in meeting the needs of such patients, and feels that an arthritis center would help meet her needs.

ENGLEMAN: Thank you very much, Ms. Brofman.

BATCHELOR: I want to respond to this account you've given, Ms. Brofman, by bringing to your attention the fact that in the course of our public hearings across the country, we've had brought repeatedly to our attention the need for counseling, for support of the several levels of professional work in this area. So, it's a message that's been very clearly given.

ENGLEMAN: Yes, Dr. Polley.

POLLEY: Before this particular session concludes, I just wanted to say that we wanted input from this area as to what your needs are, but we also wanted a perspective of what your advantages are, and that was the real purpose of my asking these questions. I think we might see this in the perspective of a model by virtue of your input in this respect.

ENGLEMAN: I think we'll now call on the next group of witnesses. Dr. Bell, Mr. Asmus, Mr. Samuel Roberts, Mr. James McNamara, and Dr. Alfred Nelson.



Several people have expressed a desire to present testimony to the Commission today without previous notice. It is regrettable that our time constraint is such that this is not possible. But I want to repeat the comment that was made earlier this morning. We welcome all written testimony; it will be looked at and, indeed, will be included in the volume of public testimony which will accompany the actual Arthritis Plan which will go to Congress. We are making a real effort to look at all public testimony, both written and oral. We are categorizing the testimony into the various channels of interest. Let me assure you that although you may not be heard here, your written testimony will certainly be had.

TESTIMONY OF  
HARRY ASMUS  
PRESIDENT  
GERIATRICS, INC.

ASMUS: I am Harry Asmus, President of Geriatrics, Inc. For those of you who may not already know, Geriatrics is a company which owns, leases, and/or manages 60 long-term care facilities. We care for approximately 6,000 chronically ill and elderly patients.

In preparing for today's meeting, I asked one of our central office staff nurses to compile a sample survey of the patients in our facilities to ascertain the approximate number of patients with primary or secondary diagnoses of arthritis. The result of this survey was that 23 percent or 1,380 of the patients in our facilities have some form of arthritis as a primary or secondary diagnosis. Although this number is significant, the national percentage is even higher. Of the 1,074,000 patients in long-term care facilities across the nation, 342,000 or 32 percent have some type of arthritis.

For a moment let's take a look at the economic impact of these numbers. If you take the figure of 342,000 arthritis victims in long-term care facilities and multiply that times the average cost of \$20.00 per day, you arrive at a figure of \$6,840,000 per day. Multiply that times 365 days a year and you arrive at a total cost of \$2,496,600,000 per year.

Now I have here a copy of the "Arthritis Alerter." Under item No. 10 it lists medical care costs annually at \$2.5 billion, but I have to think that that figure did not take long-term care into consideration. If that were done the actual total annual medical care costs would run very close to \$5 billion.

Interestingly enough, approximately 1.6 percent of our 3,700 employees have arthritis in one form or another. One of our central office staff nurse consultants--the one who did our survey, is a rheumatoid arthritic. The husband of one of our administrators has just had two hip replacements due to rheumatoid arthritis. The physical and psychological impact of arthritis hit home to me two years ago when my wife - age 28 - developed rather severe inflammatory arthritis in her knees.

However, most of the people in long-term care facilities are of the group that have osteoarthritis. Many people, including some physicians, accept osteoarthritis as an almost inevitable result of aging. In addition, since osteoarthritis is not an acute or life threatening illness, it is often taken almost for granted. However, I must say that arthritis is the one diagnosis that most affects the number of hours of patient care required. Even though the patient's primary diagnosis may be cataracts, it is the arthritis that renders the patient most uncomfortable and dependent - requiring hours of staff time to accomplish the basic bodily needs. One of the most heartbreaking situations we encounter in the long-term care setting is an elderly person whose mind is alert but whose body is a painful and distorted shell due to arthritis.

My challenge to all of us here today is to stop accepting osteoarthritis as an inevitable result of aging and start thinking in terms of prevention and cure so that we can maintain the quality of life as we grow older. Medical technology is adding years to life--but we must all band together and support arthritis, research so that life--that is quality of life--can be added to those years.

CHAIRMAN: Thank you, Mr. Asmus. Before we question Mr. Asmus, I'm going to call on Dr. Bell, whose comments I think will be connected--along the same lines.

TESTIMONY OF  
THOMAS G. BELL, M.D.  
EXECUTIVE VICE-PRESIDENT  
AMERICAN HEALTH CARE ASSOCIATION

BELL: Mr. Chairman and members of the Commission: My name is Thomas G. Bell. I am Executive Vice President of the American Health Care Association with headquarters in Washington, D.C. AHCA is the nation's largest national association representing long term care facilities. Our membership consists of approximately 8,000 long term care facilities and 600,000 beds.

Mr. Chairman, many (342,000) of the residents in long term care facilities suffer from the crippling effects of arthritis. Having seen first-hand the suffering caused by this disease, the AHCA supports a substantial expansion of arthritis research, training, public education, and treatment activities under the direction of the Secretary of H.E.W.

My purpose in testifying before you here this morning is to alert you, or to remind you, to call to your attention the significant role which long term care facilities have in providing care to arthritic patients. There are more beds, more patient-days of care provided in the nation's long term care facilities than in the nation's hospitals. Physicians and other competently trained medical personnel who provide service in the nation's long term care facilities may not have attained the status of Marcus Welby--or our facilities the TV status of Medical Center or General Hospital.

I implore you in your program planning to give appropriate recognition to the contribution which long term care facilities give and can give in greater degree to achieve the objectives of this Commission.

Mr. Chairman, in the real world of patient care in long term care facilities, most of the laying on of hands for the provision of today's patient care is done by nurses' aides. Our facilities desperately need training material geared to that level of employee.

In today's economic climate we see little ray of hope for a dramatic breakthrough in the Administration's support for better trained personnel in long term care. We are reconciled to attempting to secure piece-meal the training support needed for personnel in long term care.

We believe it would be most cost effective to have the Commission support our training efforts of all long term care personnel, but particularly that of the nurses' aide as it relates to the arthritic patient.

AHCA is making available to its member facilities almost at cost a series of training films on cassettes which are easily viewed by an individual or a group watching a rear-view projector. These are produced at a cost of five thousand dollars per film and sold for \$15.00 each.

A series of film cassettes for training of long term care personnel in appropriate aspects of arthritis would in our opinion be of significant assistance. Similar film cassettes for other categories of employees would facilitate the training process. Just one other example. In the majority of our homes, activity coordinators and volunteers provide many hours of rehabilitative activity enabling arthritic patients to enjoy a richer, more rewarding life. These individuals don't need a college education to perform this function--but simple, direct training films can assist in their effectiveness.

Mr. Chairman, our facilities want to do the best they can in the provision of care to those who suffer from arthritis. We turn to you for help in making quality care a reality for every one of our patients.

Thank you for your courtesy in scheduling my testimony here before you today in connection with my attendance at other association functions here in Denver.

I assure you of AHCA's continuous interest and support in your activity.

ENGLEMAN: Thank you very much, Mr. Bell. I think your message is heard loud and clear. Incidentally, some of the material that you need, obviously, is available now through the Arthritis Foundation, but that does not belittle the charge to the Commission to keep in mind the need for greater education for the allied health and other ancillary personnel that are now working in our long-term units.



BELL: I wonder if the Chair and the Commission would excuse Mr. Asmus and myself. We have another commitment.

ENGLEMAN: Certainly, we're very grateful to you for your presence.

BELL: We appreciate the opportunity to be here.

ENGLEMAN: Thank you. Now, Mr. McNamara.

TESTIMONY OF  
JAMES J. MCNAMARA, PH.D.  
DIRECTOR  
DEPARTMENT OF SOCIAL WORK  
UNIVERSITY OF UTAH MEDICAL CENTER

MCNAMARA: With the few minutes allowed for testimony this morning, I would like to focus my comments around the allied health professionals' involvement in arthritis, more specifically highlighting the social work involvement.

Without question, the number one priority, in my judgment is the continued pursuit of basic research toward finding a "cure" for arthritis. As a social scientist, I heartily endorse maximizing support in basic research toward this end. As a "pragmatic" man I realize a "cure" may not be imminent and for this reason I would like to extend the Commission's thinking toward placing additional high priorities on action-oriented, patient-oriented, outreach, or demonstration type projects with required evaluative research design. This in simplified form means that through a process of evaluative research we apply a scientific methodology to service and action programs in order to obtain objective and valid measures of what such programs are accomplishing.

Now for a moment let me discuss the need for such programs. During this past year I have had the good fortune of participating as a member of the Intermountain Regional Medical Program. As a team, we have designed a patient education program across four major--namely, medical, psychosocial, physical therapy, and activities of daily living. At the same time we have established a consultative clinic primarily to assist physicians in various areas with diagnostic, treatment, and resource utilization for their patients.

As part of the social work portion of the patient educational program, I have purposely designed my two-hour session to allow for patient-family interaction focused on the social-emotional problems associated with the arthritic condition. Sessions have been conducted in Las Vegas, Nevada; Boise, Pocatello, and Mountain Home, Idaho; and Salt Lake City, Ogden, and St. George, Utah. In each of these communities there has been a solid cross section of patient, young and old, male and female with mild to severe arthritic conditions. It should also be noted that these are tremendous folks that have been "biting the bullet" for years, simply living with their pain and a host of residual problems.

Allowing for the professional competence represented on the Commission, I need not spend time describing the "horror show" of some patients and families living with arthritis.

Rather, let me make a few observations from my experiences over the past year which I feel support my plea for ongoing outreach programs with the evaluative research component incorporated. Please keep in mind that the Intermountain Area is unique and its needs are likely 180 degrees different than many of our larger populated regions across this country.

1. Rheumatologists in Idaho, Nevada, and Utah are so few in number there is no way presently to assure patients will have the necessary medical expertise without programs providing consultative medical clinics and some delivery of health care services. Patients, e.g., in Las Vegas, Nevada, have a choice of driving to Los Angeles or Salt Lake City for specialized care. This added burden seems very archaic - but it's stark reality.

2. Patients are incredibly naive in their understanding of their arthritis condition, much less our health care delivery system. These people openly acknowledge that Marcus Welby, M.D., is their model even though Marcus has only one patient a week, a colleague to make house calls on his motorcycle and representing a totally unrealistic portrayal of the realities of health care today. One side of Marcus that is not absurd is the bedside manner or the humanistic approach to patient care. A good deal of the naivete is prompted by limitations of most practicing physicians to maintain a working knowledge of appropriate arthritic treatment modalities of regimens.

3. It is difficult enough for treatment of the medical component, under the above-mentioned circumstances, that often the emotional, social, financial, vocational, and sexual problems precipitated by the disease became even more obscure and the patient is lost for appropriate help in these crucial areas.

4. Although many of our problems are related to availability of solid medical expertise in arthritis, there are positive indications that resources to assist patients with a host of psychosocial, physical therapy, activities of daily living, etc., are indeed available--they require, however, mobilization and expansion of services to include the arthritic. As an example, let me briefly cite our experience in Boise, Idaho. During the past year our team has made several visits to Boise with both clinic and patient-education programs. At the onset we solicited cooperative and professional collaboration from the local professional community utilizing the Arthritis Foundation Chapter as our hub of operation. This community has successfully rallied its professional team of social workers, nurses, physical therapists, occupational therapists, and several interested physicians and has made strides toward a self-sustaining program requiring only occasional medical consultation from a rheumatologist. I have every reason to believe that the arthritic patient will have optimal care in the Northern Idaho area.

This occurred because a community of professionals were willing to work with other experts toward a common goal of enhancing the care of



arthritic patients - recognizing their ongoing responsibilities and capitalizing on a short-term program to achieve a self-sustaining and ongoing local program.

In concluding, I hope the Commission takes into consideration the unique needs of various regions and will look to many of us who have been in the trenches to assist with plans for better serving our arthritics.

I sincerely hope provisions will be made available for continued outreach, demonstration-type programs to include patient and physician education and the potential for assisting communities enhance their health delivery system toward helping them help their own. This includes the potential for treatment of the total patient and his family with full recognition of the impact arthritis can have on an individual, his family and the community.

Plea - protect dollars - no other source of funds.

Major problem in future - Patient care, access to health - not insurance - networks.

Education - greater cost-sharing of tuition.

ENGLEMAN: Mr. McNamara, I don't remember exactly how you put it, but you made some comment to the need for some scientific evaluation of the ongoing work with regard to the outreach program. Will you elaborate on this just a little bit?

McNAMARA: I think there's been a tendency, Dr. Engleman, to relate research only in the area of basic research, perhaps following the medical scientific model, if you will. But the keynote and the definition of evaluation are probably threefold. First, there has to be an objective or a goal which is considered desirable or has some positive value. The second component is that there has to be a planned program of deliberate intervention in which one hypothesizes or is capable of achieving this desired goal. The third is that the method for determining the degree to which your desired objective is obtained as a result of the planned program is definitely related. I mean that when we think about evaluative research, we're thinking about, indeed, a new area that I think has great potential for these kinds of demonstration projects.

BATCHELOR: Dr. Engleman has essentially introduced the question that interests me, interests all of us here. I wondered, against that general background, your experience with the Intermountain Program and the efforts of evaluation there, whether you had any recommendations to the Commission based on this specific experience?

McNAMARA: Unfortunately, we're in the process right now of evaluating what we've been doing for the last two years. I'm sorry that I'm having to make some generalizations, but I do have some kind of "gut" observations that I have included here. Perhaps within the next six months we would have some additional detail, and we'll assure you of getting it through our friend, Mr. Shields.



ENGLEMAN: I know that the RMP's, the Regional Medical Programs, are going through the process of attempting to evaluate their programs.

We will now call on Dr. Alfred Nelson. Dr. Nelson.

TESTIMONY OF  
ALFRED C. NELSON, PH.D.  
MEMBER  
MAYOR'S COMMISSION ON AGING  
ADVISOR  
COLORADO COMMISSION ON AGING

NELSON: I am a retired faculty member and administrator of the University of Denver and have been interested in the elderly in the City of Denver since 1957 when I was asked to be chairman of a committee of the Denver Area Welfare Council, now the Metropolitan Council for Community Service, for the purpose of assessing the situation in the city as it affected the interests of the older citizens of this community. Out of the meetings of that committee over a two-year period there evolved a Senior Citizens Council and a Mayor's Commission on Senior Citizens. This body was instrumental in the establishment of the first Senior Center in the city under the auspices of the Denver Department of Parks and Recreation to make available to those interested the services of such a center. From this beginning there are now six such centers and one more in the planning stage under city auspices, and many privately sponsored centers throughout the city.

There is now a Mayor's Commission on the Aging, established by the City Council as a successor to the original informal group. I am currently a member of the Mayor's Commission on the Aging, an advisor to and former chairman of the Colorado Commission on the Aging and past chairman and currently a member of the Board of Directors of the Colorado Congress of Senior Organizations. I have also served on the Advisory Board of the Senior Centers sponsored by the Department of Parks and Recreation and have long been interested in the Federation of Organizations of Older People which represents the interests of about 50 organizations in the metropolitan area.

When Dr. Cleere called me to see if I would be interested in appearing at this hearing, I told him that, unfortunately, I had little experience with this universal ailment, even though I was one of the victims, to small extent, of its limitations. But the connections which I had, through the years, with the elderly certainly made me interested in any effort being made to improve the situation as it affected the elderly in our society. I was reminded of the concern voiced by one person who said that there was a lot of talk and attention given to the various "isms" such as fascism, nazism, racism, communism, activism, and the other "isms" but one very seldom heard anything about rheumatism. Of course that is due to the current use of the term "arthritis." It also reminded me that I frequently wish that I were young and romantic instead of old and rheumatic. Be that as it may, the elderly have a much larger chance of being affected by the problems relating to arthritis than probably any other group in our society.

When one gets into the question of what are the major problems of the elderly, he finds that they fall into several main categories which are made more acute by the prevalence of arthritis among the elderly. One of these is health itself in which arthritis is such a great factor. With the rapidly escalating cost of health care the cost of arthritis treatment is a serious matter and is linked inextricably with the second of the major concerns of the elderly, namely, the matter of income which is too often limited and, in most cases a fixed item regardless of the cost of living. Hence if some less expensive method of dealing with the arthritis problem can be found it will be a bonanza for many. The cost of drugs, pain killers, and related items for people who suffer from arthritis is a serious matter for older people.

There is much said these days about the isolation factor which enters into the lives of many of the elderly. Arthritic individuals, especially those suffering from the crippling type, have limited mobility which is an important deterrent to getting out and mingling with others. When an individual finds it impossible or very difficult to get around because of arthritis it is an important factor in the tendency toward isolation. Thus arthritis is a real factor in the problem of isolation for the elderly.

Another element of limitation on older people is that of transportation. The inability to drive a car and reliance on public transportation is one of the serious limitations which older people have to face. It is a well-known fact that arthritis contributes immeasurably to that phase of life in many cases. Thus, anything which may alleviate this problem is important. There are many moves in the direction of better transportation for the elderly and a few of these are in the direction of making it easier for the elderly handicapped to get to shopping and other activities but, more important, to get to medical centers, both public and private for treatment. The surface has only been scratched so far.

Another very important element in the welfare of the elderly is that of living arrangements. Many older persons would like to remain in their normal environmental surroundings but the crippling effects of arthritis mitigate against this desire on their part. Anything that can be done to enable them to remain in their own homes rather than going into an institution will remove a serious obstacle to normal living.

With the increasing number of elderly we will have a greater susceptibility to the incidence of arthritis because of lower vitality and other elements which enter into the tendency of individuals to develop the disease. Thus it is important for studies to be made on the incidence of the disease among the elderly, and to find ways of preventing it at an early age and to reduce the susceptibility of people to it, especially among the elderly. It is my hope that the start which has been made will improve the life-style of many of our elderly.

To return to the senior centers, one of their values is that of allowing the mingling of individuals and getting their minds off themselves. Group relationships are in themselves a form of therapy which can relieve the distress which many feel who have an arthritis problem.



Here is where the element of mobility comes in. Studies need to be made on the prevention and alleviation of arthritis. I commend the Commission. But it is my purpose, too, to emphasize the factors other than the medical, which make arthritis an important concern to all of us. Thank you for this opportunity.

ENGLEMAN: Thank you very much. We'll now call on the next group of witnesses. Mr. Heitler, Dr. Hollister, Dr. Cleere, Dr. Evans, Dr. Anderson, and Mr. Runyon. We'll now call on Mr. Heitler.

TESTIMONY OF  
EMMETT H. HEITLER  
VICE-PRESIDENT  
GENERAL ROSE HOSPITAL

HEITLER: My name is Emmett H. Heitler, and, having recently retired as Chairman of the Executive Committee of Samsonite Corporation, I am now making a second career of voluntary activity in the health care industry and am especially interested in preventive medicine. I am immediate past president of the National Jewish Hospital and Research Center at Denver, first vice president of General Rose Memorial Hospital at Denver, and executive trustee of the Eleanor Roosevelt Institute for Cancer Research located at the University of Colorado Medical School. With this in mind, I felt I could perhaps be helpful in interpreting for you the need for industry to have a better understanding of the problems of arthritis.

Recently we contacted eight industries in the Denver area, namely: Mountain States Telephone Co., Johns-Manville, Gates Rubber Co., Adolph Coors Co., Public Service Co., Samsonite Corporation, Martin Marietta, and Dow Chemical Co. -- and also the Workman's Compensation office. All of the people contacted in industry knew of instances where a valuable individual had been forced to take an early retirement due to arthritis, or where an employee had to be transferred to a less productive job, but, actually, there was no awareness of the cost or problems presented by the occurrence of arthritis, and there was no data available on this subject.

Many years ago I can recall we were in a similar posture regarding industrial safety, and it was not until we created a safety consciousness or safety awareness that we were able to reduce the human suffering and the cost of accidents.

More recently, in the matter of ecology, with regard to air pollution, water pollution, sound pollution, and the like, it is only after these matters were brought to the attention of industry and the general public forcefully that anything was done to correct the shortcomings in this area.

I believe that we can create an awareness not only in industry but in the general public to reduce the horrible suffering and the resultant costs due to arthritis. I believe this can be done through the establishment of the proper type of arthritis center located strategically throughout the United States, and I would like now, in concert with physician researchers, clinicians, and administrators, to offer several



suggestions concerning an arthritic center. In effect, I believe we are suggesting a specification for such a center.

We believe that an arthritic center should be a functional unit and not a structural facility. We see in our community existing facilities, all non-competitive, such as those concerned with basic research, patient care, and clinical research and teaching, and outreach programs which could be incorporated into a functional unit.

For example, in Denver we conceive of a center including the University of Colorado Medical School, together with its arthritic research laboratory; the General Rose Memorial Hospital Treatment Center, with beds for care of acute, critical patients; the National Jewish Hospital, with both basic and clinical research and beds devoted to the long-term care of patients and with an outreach program available to arthritics in surrounding communities; and the Eleanor Roosevelt Institute for Cancer Research, where basic studies in the mammalian cell are revealing knowledge pertinent to arthritis. All these organizations, together with the Arthritis Regional Medical Program serving the states of Colorado and Wyoming, should be joined together as a Regional Arthritis Center.

The speakers who follow will indicate how their individual capabilities can function in a center setting. The center should be an organization to unify all of these efforts, thus avoiding duplications and offering comprehensive patient care, teaching, outreach, and, above all, basic research.

ENGLEMAN: Thank you, Mr. Heitler.

We will now hear from Dr. Hollister.

TESTIMONY OF  
J. ROGER HOLLISTER, M.D.  
PEDIATRIC RHEUMATOLOGIST  
NATIONAL JEWISH AND COLORADO GENERAL HOSPITALS

HOLLISTER: Arthritis in children poses some unique problems which are capable of solution through the Arthritis Act in regional centers such as Denver, Colorado. As you have heard from my colleagues, Jane Schaller in Seattle and Virgil Hanson in Los Angeles, children's arthritis is significant in numbers, alone, with 250,000 cases existent in the United States of juvenile rheumatoid arthritis. Those figures don't include patients with systemic lupus erythematosus, dermatomyositis, or chronic orthopedic problems affecting the joints which also need expert medical care by physicians trained to care for these children.

Rather than review each disease I would prefer to describe and give examples of the challenges which underlie all chronic arthritis in this age group. Chronic illness is different in children because it occurs in the setting of physical and emotional growth. How joint inflammation distorts the length of an arm or a leg or the jawbone is partly known. How chronic illness affects a child learning to walk, to ride a bike, to start school is almost unknown. Even less understanding is available

about a child entering adolescence when he or she should be establishing their own identity, self-reliance, and independence. How does a child become an independent, self-sustaining adult if they have had to live with an illness so prone to sponsoring dependency on others. If one has had to rely on parents and siblings for medications, doses, physical therapy, school excuses from P.E., transportation, how does that child develop the inspiration, means, and confidence to graduate from school, to find employment and to fashion a life style of their own. Our knowledge of how to help these children is limited now to an awareness that it can be done.

Let me give you an example or two. Linda is a 23-year-old woman with arthritis since age 12 who I first saw at age 21. At that time, she had graduated from high school but was wholly dependent on her parents for transportation, dressing, meals, toileting, and all socialization. The day-to-day focus within the family and the four younger siblings was on Linda's limitations and how to cope with them. After two years' work, coordination, surgery, etc., Linda was in her second year of college, worked part-time in the university library, had moved into her own apartment and established herself in our society. The cost in hospitalization, human effort, social agencies, etc., was immense because problems had to be undone which need not have become fixed and immutable if preventive measures had begun when her arthritis started. The costs of rehabilitation of this patient will be written off in the future as she becomes a wage-earning, tax-paying citizen rather than a ward of our social security system.

Monica is a 9-year-old girl with scleroderma, a disease for which there is no treatment, who has been confined to a wheelchair for the past two years. She was confined to her house where her parents were becoming demoralized with each passing day. After a hospitalization at National Jewish Hospital, the child and family are now able to cope with the illness and enjoy a quality of life within the confines of Monica's illness. She now attends regular school, socializes with her peers, and went to a handicapped camp this summer. And these adjustments were possible in a small town in Colorado, 150 miles from Denver. These two examples are extremes of difficulties encountered in the care of each child with arthritis.

Therefore, I believe that arthritis in children needs special attention in the planning by your Commission. In Denver and at the National Jewish Hospital chronic illness in childhood has been studied and cared for over many years. Although respiratory illnesses had predominated in the past, in the past year the beginnings of a coordinated approach to children's rheumatic diseases had begun. Physical therapists, occupational therapists, social workers, psychologists, psychiatrists, counselors and nurses have been organized and taught a comprehensive approach to children's arthritis. At present this has largely occurred in an in-patient setting, which could serve as the nidus for a regional center. The entire program is fully integrated with the University of Colorado Medical Center just four blocks away and has been a teaching resource for trainees in medical and paramedical fields.

I heartily support the concept of arthritis centers and wish to propose that the National Jewish Hospital and University of Colorado Medical Center serve as such a center in the Rocky Mountain area.

ENGLEMAN: Thank you, Dr. Hcllister.

Dr. Anderson.

TESTIMONY OF  
STEVEN JAY ANDERSON, M.D.  
MEDICAL DIRECTOR  
ARTHRITIS PROJECT  
REGIONAL MEDICAL PROGRAM, INTERMOUNTAIN REGION

ANDERSON: Mr. Chairman, and members of the Commission: My name is Steve Anderson. I am the Medical Director of the Arthritis Project of the Regional Medical Program in the Intermountain Region.

Mr. McNamara sort of ran down my speech, so I'm going to dispense with that and only cover one aspect which I'm sure the Commission has some interest in, and that is postgraduate medical education. In casting about to find something that would fulfill the needs of the region, we discovered some very serious things. Number one was that the level of care rendered by family practitioners and general internal medicine people was far below the standards that we had anticipated. We used as a parameter for measuring this the use of physical therapists, and we found that the use of physical therapists by these people in these professions was, for all intents and purposes, nonexistent. We felt that, this reflected, then, a major need in our region; that is, of educating the providers of care.

We also recognized that the number of rheumatologists is extremely low in our area, namely, one per state in private practice, so that depending on them to cause an impact for an improvement in the care of arthritis in those areas was really foolish; and that our whole effort, as far as improving the care that doctors give, really involved educating the general practitioner and the people in general internal medicine.

In casting about to find a model for this, we discovered a clinic that is being run and was started by Drs. Healey and (inaudible) from Seattle, and is in Lewiston, Idaho, which is just across the border from Washington. I went up there to observe this clinic, and found it was a very new thing. What happens is that the rheumatologist comes down from Seattle. He then has the private physician bring in his patient to the hospital and present that patient to the rheumatologist and to members of an arthritic team, physical therapist, occupational therapist, social worker, and a community nursing representative. After this presentation, the patient is seen by the team, mainly the rheumatologist, and then the patient has left and is discussed with the physician and with members of the team.

It was very apparent when I was in Lewiston, Idaho, that this rather rural place had a high level of expertise in arthritis care. It was much



greater than in any other rural place that I had been in; and, in fact, was greater than in some of the metropolitan areas in Utah. I talked with Dr. Healey to a great extent about this, and he indicated that one of the very gratifying things that he has seen at this clinic is that there has been a very great observable change in the way arthritis care is dispensed in Lewiston, Idaho.

When we observed the clinic, it had been going for five years. That's quite a long time, and it was very well organized at that point. So, taking this for a model, when we tried to get other things going in different places in Idaho, Nevada, and Utah, we met with some resistance; but, overall, our experience has been extremely gratifying. I think that this represents a very favorable model that the Commission should favorably consider for incorporation in the recommendations as to postgraduate medical education.

ENGLEMAN: Thank you very much, Dr. Anderson.

We will now call on Mr. Runyon.

TESTIMONY OF  
ROBERT V. RUNYON  
PRESIDENT  
OREGON CHAPTER  
NATIONAL ARTHRITIS FOUNDATION

RUNYON: Dr. Engleman, and members of the Commission:

This may come as a surprise to you, but I am not a physician, nor am I member of any allied health profession, nor do I have arthritis. I am here today because I am an individual who feels an empathy for those unfortunate enough to be afflicted with this disease.

I am a volunteer associated with the Arthritis Foundation for more than 25 years. I am currently President of the Oregon Chapter of the Arthritis Foundation. I also serve as the Executive Committee Regional Director for Region VIII, which consists of the States of Oregon, Washington, Idaho, Montana, Utah, Colorado, and Arizona.

I have within just the past two weeks attended a meeting of the Budget and Plans Committee of the Arthritis Foundation. I listened, as the chairman of that committee, to an impassioned plea by two prominent medical doctors who are heavily involved in the Arthritis Foundation's activities. They explained the urgent need for additional supplemental funds for medical center grants and research fellowships. This year the Arthritis Foundation will experience, approximately, a one-half million dollar deficit occasioned by appropriation of supplemental funds of almost that amount for this same purpose in 1975. It should be obvious that continued deficit financing of this sort would be disastrous to the Arthritis Foundation; yet, the need for these funds should be equally obvious.

It would be my suggestion that a most appropriate use of any funds available under the National Arthritis Act would be assistance in funding arthritis research centers, and providing incentive for medical school students to follow rheumatology as a professional path, and to promote the development of additional physical and occupational therapy clinics.

I appreciate the opportunity of appearing before this Commission, and I hope that in its wisdom it will be able to make significant contributions to the effectiveness of the National Arthritis Act. Thank you.

ENGLEMAN: Thank you very much, Mr. Runyon. Are there any questions from the members of the Commission?

I think you have made yourself quite clear. Thank you very much.

We'll now call on the last group, last but not least in importance, Mr. Poole, Dr. Long, Dr. Norton, and Mr. Porter Nelson.

I'd like to call on Mr. Poole.

TESTIMONY OF  
H. M. POOLE, JR.  
HUSBAND OF ARTHRITIS PATIENT

POOLE: Mr. Chairman and distinguished members of the National Arthritis Commission:

My name is H. M. Poole, Jr. I reside in La Jolla, California, with my wife who is severely afflicted with a disease familiar to all of you, rheumatoid arthritis. I am, therefore, painfully and intimately aware of the terrible toll which this little understood disease can wreak upon individuals, regardless of their economic or social position, their age, or their previous state of health.

I am recently retired from Johnson and Johnson, where I was a director, member of the Executive Committee, and Vice Chairman of Johnson and Johnson International. In my work with Johnson and Johnson I was in daily contact with the production and distribution of medical items for use by medical institutions, professionals and patients, one aspect of which I would like to briefly comment on later.

I currently serve as a director of Scripps Memorial Hospital, and Vice Chairman of the Arthritis Foundation, the only nationally based voluntary health agency solely concerned with arthritis. Through my association with the Foundation, and as the mate of an arthritis victim, I have become increasingly aware of the many unmet needs in this field of medicine, and have become convinced that only a national effort, surpassing even that proposed in the National Arthritis Act, combining resources of both the public and private sectors, will begin to provide some long overdue solutions to the manifold problems confronting the arthritis community.

The plight of today's victim of arthritis, particularly when the disease takes one of its more severe and systemic forms, such as

rheumatoid, lupus, or sclerosis, is frightening. There are, as you well know, too few medical professionals who understand this disease in respect to its complicated diagnosis and demanding management, and those that are educated in the disease are often frustrated by their lack of tools with which to treat the aggravating symptoms.

Too often, as we know, the general practitioner who encounters an arthritis patient echoes the title of a recent Broadway play, "Don't Bother Me, I Can't Cope!"--an attitude which too frequently threatens to become the lifelong story of the arthritis patient as well.

This debilitating disease with its critical psychological aspects, brought on by the chronic nature of the problem, the constantly recurring searing pain, and the frequent but unanticipated remissions which raise one's hopes for the moment, only to dash them to the ground the next as the disease remounts its attack with even greater violence than before, must begin to receive more attention than it has to date, which brings me to why I consented to your chairman's request to appear before you today.

Currently, between the various institutes of the National Institutes of Health, the Arthritis Foundation, and other major private philanthropic foundations, approximately \$20 million is made available for arthritis research, including the training of new researchers. For a disease which disables 3.5 million Americans, and to whose previously employed victims the Social Security Administration currently is paying \$1 billion a year in disability benefits, plus another one-quarter billion dollars annually to dependents of disabled arthritics, our investment to try to reduce the tremendous economic impact of this disease is absurdly low by whatever standard one chooses to apply. With these facts as a starter, consider the tremendous financial impact on industry and the resulting increased cost of their products.

In recognition of the growing need to stimulate new research into the possible causes of arthritis, the Arthritis Foundation this year has pledged to increase its commitment to the Arthritis Clinical Research Centers Program by 75 percent, agreeing to take this additional money from accumulated income if our current fund raising efforts prove inadequate to the task.

Actually, if it were possible, this increase should have been 750 percent, for even now we are only able to provide \$20,000 per center to 44 institutions. If the support were to regain the impact it had in 1966 when the program began, each center would be receiving \$140-\$150,000.

The Arthritis Foundation also supports the training of post-doctoral fellows in rheumatology. Currently, we are financing the advanced study of 65 such persons, about three times as many as the Federal Government.

Thus, while we are encouraged by the promises inherent in the National Arthritis Act, like all promises on overdue debts, we are growing impatient to collect.

One research area of special concern to me, which I believe could benefit substantially from an expanded effort, is that of new drug trials.



As reported in the Bulletin on the Rheumatic Diseases last year, over 70 nonsteroidal anti-inflammatory drugs have been developed in the past several years by drug companies in this country and abroad, yet few are yet approved for general use in the U.S.

In order to expedite the release of these drugs by the FDA, it would appear that we are in need of at least four things to occur almost simultaneously: (1) more research money, (2) more researchers, including the wider use of non-M.D. researchers, (3) more drug testing, and (4) improved animal models.

Roland Moskowitz, M.D., of Case Western Reserve University, when testifying before the Senate on the National Arthritis Act legislation last year, cited a specific example of the lack of adequate personnel in his own laboratory in which he is only capable of testing one, or at the most two, new drugs each year. Yet, by tripling or quadrupling the number of research personnel, seven or eight new drugs could be tested in this same laboratory.

This example can be uniformly duplicated, I am told, throughout the country.

Much of the arthritis research problem obviously lies in the critical lack of academic rheumatologists. However, should we be placing so much reliance upon these specialists for much of the rather mundane and routine investigatory work associated with drug trials? Cannot the responsibility for these trials be broadened and the level of expertise required re-evaluated in order that a new dimension be given to this important task through the availability of additional personnel?

Lastly, although I, like most others, want to see arthritis research speeded up, perhaps the question of what "centers" should be, where they should be, how many there should be, and how they should be staffed, is too narrow an approach to a problem which concerns 20 million "centers," for, indeed, each patient is the primary center of concern to all of us, not the institution to which he or she is referred for treatment. That should be the secondary center of concern. We need to be extremely careful not to reverse this order of magnitude of the problem, for if we do, we will be missing out on where the action is, or at least where it should be.

In the Arthritis Foundation's statement on policies and rules governing grants to Clinical Research Centers, which is appended to my statement, there are 13 eligibility criteria listed. The first three deal with the research and teaching qualifications of the applicant institution. The remaining ten criteria concern the institution's capabilities in respect to its patients. That's about a 77 percent patient orientation, which to my mind is minimal. The Commission may wish to consider the incorporation of the Foundation's criteria for centers in its consideration of this area of the Act.

Thank you, Commission members.

THE ARTHRITIS FOUNDATION'S STATEMENT ON POLICIES AND RULES GOVERNING GRANTS TO CLINICAL RESEARCH CENTERS

GENERAL INFORMATION

The Arthritis Foundation will consider applications for grants to medical schools, their teaching hospitals or other qualified hospitals or medical institutions to help support Arthritis Clinical Research Centers to conduct relevant clinical research, perform noteworthy teaching and encourage exemplary patient care.

The principal objectives of such programs must be to:

- (1) Facilitate the search for new knowledge of disease mechanisms.
- (2) Develop new or improve methods of treatment including rehabilitation.
- (3) Expand graduate and undergraduate teaching programs.
- (4) Establish standards for comprehensive, exemplary inpatient or outpatient care to patients with arthritis.
- (5) Establish standards for comprehensive diagnostic and therapeutic consultation services to referring physicians concerning patients with arthritis.

Prerequisites for support are an approved Director and the participation of a multidiscipline professional staff in long-range comprehensive patient care, such as, a rheumatologist or internist, pediatrician, orthopedic surgeon, nurse, physical therapist, and medical social worker. Other specialists may be included in the team, depending upon the individual center program. It is also desirable that specialists, such as a biochemist, immunologist, physiologist, pathologist, psychologist or microbiologist collaborate in the analysis and research of problems perceived in the care of the patient.

Acceptability of each patient will be determined by the center staff. Compliance with the Eligibility Criteria, which follow, is required.

ELIGIBILITY CRITERIA

- (1) The facility must be a medical school, its teaching hospital or a qualified hospital or other medical institution accredited by the Joint Commission on Accreditation of Hospitals.
- (2) The institution must be noteworthy for quality research and the chief investigator or the medical director of the proposed program must be well qualified to conduct clinical research.
- (3) The institution must be noteworthy for quality teaching and the chief investigator or the medical director of the proposed program must be well qualified to conduct clinical teaching.

4. The available facilities must be adequate to conduct a program of clinical research and clinical teaching.
5. There must be daily medical supervision of each inpatient's treatment program by well-trained physicians skilled in the management of arthritis.
6. There must be a complete medical staff with representation from all applicable specialties.
7. Qualified personnel to provide nursing care to meet the specific needs of long-term patients and their families and to instruct the family and attendant in the care of the patient at home must be available.
8. Qualified personnel to provide physical and occupational therapy, including evaluation of the patient's functional ability and instruction of the patient or parents in home treatment and activities of daily living must be available.
9. There must be qualified personnel to provide social work to help patients and their families to develop constructive attitudes about the disease and the need for long-term medical treatment and rehabilitation; and to provide or help secure from appropriate agencies, practical assistance to solve related educational and socio-economic problems.
10. Educational and vocational planning.
11. Adequate available equipment for surgical, laboratory and physical therapy services and accessible facilities for bracing, splinting and assistive devices.
12. Individual evaluation of the patient leading to a program specifically designed to produce optimal function.
13. Provision for continuity of care of patients by:
  - a. proper predischARGE instruction of patients, families and appropriate home care personnel.
  - b. a system for long-term follow-up.
  - c. consultation, care or re-admission for emergency and additional treatment or evaluation.

ENGLEMAN: Thank you, Mr. Poole. We will look at these criteria with great interest, I assure you.

Dr. Long.



SUBMITTED STATEMENT OF  
ROBERT S. LCNG, M.D.  
ASSOCIATE MEDICAL DIRECTOR  
MUTUAL OF OMAHA

I. Abundant statistical evidence exists as to the frequency of occurrence, the longer hospital confinements, the numbers adjudged totally disabled by Social Security disability standards or insurance companies--AND--we expect these statistical totals to increase despite any medical treatment improvements. This increase prediction will be discussed later.

The most recent data we possess shows that our own company's experience closely parallels that described in Social Security Administration, the Commission on Professional and Hospital Activities, and the Arthritis Foundation's publications. For example, people in the childhood and working years ages, protected by group insurance, average one day of hospitalization more per confinement than the "norm" confinement. Our Medicare branch reports that those in that age grouping generate an average confinement exceeding the Medicare norm by two days. The percentage of surgical to nonsurgical confinements is, of course, quite high due to the outpatient treatment modalities commonly found.

One difficulty we note is that literally all of the commonly available statistics approach the variety of conditions you are concerned with on a gross, rather than discrete, basis. In most cases (my own company included) disability codings for claims are less precise than is desirable.

II. From a joint Insurer-Arthritis Commission standpoint, there are two areas of concern which are applicable in any long-term ailment which has the potential to create permanent partial or total disability.

- (1) Hospital-Medical-Surgical coverage, and
- (2) Disability income protection

From your standpoint, the questions involve:

- (1) Availability of coverage
- (2) Cost
- (3) Limitations

From our standpoint, the question is one of just how far we can go without sustaining unbearable losses.

The first comment I wish to make involves a truism of the insurance business that has been immutable, despite governmental tinkering, to this time. That is the fact that a person afflicted with a serious condition will face potential personal financial disaster unless he or she is either rich or very poor. They are well taken care of one way or another.

The great mass of our population identified as the "middle-class" is the group truly threatened by any severe illness or injury. The fact that inflation/recession has reduced discretionary income as a percentage of total income serves to reduce the numbers of dollars which will be devoted to individual purchase of insurance products. Only a change in our national economic picture can cure this, neither an insurer nor an association or commission can be of help.

In terms of group Hospital-Surgical-Medical coverage, it seems fair to state that the middle class is in reasonably good shape--as long as the family breadwinner is able to work. The spread of group insurance has been extended to constantly increasing numbers through various mechanisms, and group insurance has always had the built-in advantage (to the individual) of disregarding existing health conditions of the actively employed and their nonconfined dependents.

The coverage provided under group programs has steadily improved. Mutual of Omaha, as one of the "top ten" group insurance underwriters in the country, has noted:

- (1) First, a slow movement toward the inclusion of catastrophe protection (Major Medical) in its buyers' contracts,
- (2) Second, a snowballing trend in this direction until today the vast majority of our group insurance customers provide this coverage to their group members (84 million now have this coverage), and;
- (3) Finally, a surge to increase the maximum benefits available. Where \$10k and \$25k were standard a few years ago, now \$50k, \$100k and \$250k maximums are common. Today 80 percent of all have maximums above \$20k.

The significant factor is that this is not a trend peculiar to Mutual but is found throughout the group insurance business.

For years, disability income protection was an afterthought to group insurance purchasers. Benefits were rarely provided for periods exceeding 26 weeks and the benefits themselves usually bore little relation to the group members' normal earnings. Total families protected on a short-term basis has remained around 50 million for some years. The rise of group Long-Term Disability protection during the last decade has served to protect people (4 million families in 1968; 15 million in 1973) during the entire span of normal working years and in significant dollar amounts. We expect this trend to continue.

As a side area of concern, the individual hospital-medical-surgical conversion policies made available to those leaving groups due to total disability have generally been improved in recent years even though carriers lose money on these contracts.

At the individually purchased policy level, the situation is different. Just as many dying people wish they had purchased more life insurance when they were insurable, so do many people afflicted with

inflamed joints and connective tissues suddenly perceive the values of individual health insurance coverages.

If insurance companies were truly the cold-blooded entities some try to claim, we would offer no coverage to anyone with an identifiable arthritis condition. The situation is as I have previously described--we do the best we can without working undue hardship on our other policyowners. Further, in the case of Mutual, we periodically review our experience with the hope of being able to broaden coverage.

Today, our underwriting can generally be described as follows:

- (1) Only asymptomatic/incidental conditions, discovered in the course of other Medical attention or treatment, are considered as "standard" risks, i.e., no elimination periods, no limited benefits, no "rate-ups."
- (2) Other conditions, such as Rheumatoid Arthritis after five years' duration and controlled Gout may be discretionarily underwritten on a limited benefit basis and at higher rates.
- (3) Some conditions, such as Rheumatoid Arthritis during its first five years, and "disseminated" Lupus, remain uninsurable.

These, then, are the things insurers can do today. We would like to think that we will do more tomorrow. Unfortunately, a threat to our capacity of even continuing today's activities has arisen - and it is this that I wish to bring to your attention.

One of the conditions you are concerned with, Osteoarthritis, described in the Arthritis Foundation's "Basic Facts" booklet as:

...principally a wear and tear disease of the joints which comes with getting older. It is usually mild and is not generally inflammatory. It does not cause general illness. SOMETIMES there can be considerable pain. Mild to severe disability may gradually develop.

Osteoarthritis has become a substantive problem for insurance carriers.

This has been due, in our opinion, to deliberate abuse of existing disability benefit programs, primarily Social Security disability benefits.

Insurers today are finding far too many policyholders whose coverage was issued on the asymptomatic/incidental basis who suddenly, without any substantive change in objective Medical evaluation, are claiming to be totally disabled. Our problem has been exacerbated by the Social Security situation. During the last decade, Social Security disability data shows:

- (1) A 258 percent increase in disability applications.
- (2) A 210 percent increase in initial disability awards.



- (3) A 321 percent increase in ultimate awards of initially rejected applications

BUT

- (4) Only 48 percent increase in the number of Social Security eligibles.

As osteoarthritis is firmly fixed in third place among disabilities of the middle aged in Social Security data the magnitude of the problem is apparent.

Once a Social Security disability award has been made, it is literally impossible to deny disability income benefits under individual or group insurance policies.

Additionally, Social Security notes definite patterns in the filing of disability applications with areas of highest unemployment producing more applications than stable areas.

We believe that your statistics as previously mentioned have been skewed by this situation and your foundation and the Commission itself have innocently and unknowingly been placed in the position of representing the illegitimate along with the genuinely disabled person.

From our standpoint, we resent being literally coerced by consumerist courts to provide "retirement benefits" to people who could work, out of policy reserve funds accumulated to protect those who truly can't work. While our situation is not yet "critical" it has moved only in that direction for several years.

The upshot of this could be an underwriting retreat which none of us wants.

Both as an individual company and member of an industry we support the goals and efforts of the Commission in developing a National Arthritis Plan.

Our own industry organization, the Health Insurance Association of America, has expressed industry willingness to create state "insurance pools" to provide coverage to the currently uninsurable, the unemployed and the near poor (all of which will include Arthritis sufferers). We only need legislative action by the individual states to implement programs of this sort.

As individual companies, Mutual (and we would assume, all major companies) support local fund campaigns, some of whose monies go for Arthritis uses. Quite often we donate personnel time as well as dollars.

Mutual is one of 15 major insurers (and more are coming) who financially support the Insurance Medical Scientist Scholarship Fund, some of whose scholars are involved in learning to become research and teaching specialists, some of whom will be working in the field of Arthritis.

Currently 24 such scholars in the M.D./Ph.D. program are being fully supported by the insurance industry.

In addition, many insurers, including Mutual, actively promote rehabilitation programs and provide funding for individual insureds to become physically and/or occupationally rehabilitated. Dr. Howard Rusk, head of the Institute of Rehabilitation Medicine, was an early recipient of our company's Criss Award and continues with us as a consultant in this program.

Your outlined activity for the near and long term is impressive, but due to a slightly different perspective we feel it may be desirably expanded.

We would ask your consideration of a broadening of your future activities to include:

- (1) The adoption of unequivocal positions with public and private disability entities opposing those who seek to pervert the process of financing genuine disabilities.
- (2) Promoting the use of the forthcoming Comprehensive Arthritis Centers as definitive determination points of the existence and degree of claimed arthritic disability. This work, made available to both public and private entities could become the greatest guarantee of properly and appropriately spent monies. Protection of the legitimately disabled from those who would seek to pervert the intent of benefit programs is something you can help greatly with - and - we ask that help.
- (3) Finally, we need to find some way to develop information to go with our numerical statistics to tell us about the severity of the arthritis or the degree of disablement as well as the treatment needed.

For example, it is not too helpful, and may be misleading, to find and emphasize in publicity releases that there are 20 million people seeking medical care for arthritis, of whom 12 million have osteoarthritis. How many of the latter really need any significant amount of treatment? How disabled are they really? How many are housewives over the age of 55 or 60 who are not otherwise employed and are quite able to do their housework? We need a better breakdown by age group and employment status as well as severity and need for treatment.

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TESTIMONY OF  
ROBERT S. ICNG, M.D.

LONG: Mr. Chairman, and members of the Commission: I am Dr. Robert Long, from Omaha. I am an internist in private practice there, with a particular interest in arthritis. I am also a part-time Associate Medical Director and consultant for Mutual of Omaha. In the latter capacity, I am also a member of the Council on Consumer and Professional Relations of the

Health Insurance Association of America. That is a trade association of 300 of the largest health insurance companies.

I want you to know that my company, Mutual, as well as other companies in the industry certainly endorse and applaud the work of this Commission. I think you know that the industry, through its individual companies, has always supported the work of the Arthritis Foundation and arthritis clinics, both on the local and the national level. I want to give you a quick illustration of something going on now in that regard. We have what is known as an Insurance Medical Scientist Scholarship Fund, which came into existence about three years ago, at about the time NHI had to drop a good many of many of its M.D. and Ph.D. scholarships for lack of funds. This fund that we have organized in the industry now is supporting students in the M.D.-Ph.D. scholarship programs at various universities. As most of the members of the Commission know, I'm sure, these are men who are committed to a lifetime of basic research and teaching. Of course, a fair number of these will wind up in rheumatology, as well as in other areas and endeavors.

I want to report to you that the situation with respect to arthritics and insurance has improved remarkably in the last 10 years. This has come about largely through the increased availability and widespread use of group insurance mechanisms. Again, this has become more widespread so that the great majority, or virtually all, employed persons, in groups of five or more, are covered by some kind of hospital, medical, surgical insurance, and at least limited disability income insurance.

This insurance is not only more widespread, but the aggregate benefits have been increasing from a former average of around \$10,000, now to in excess of \$20,000 on the average. Many plans are now going at \$50,000, \$100,000, and even \$250,000 aggregate benefits. As you know, this is important under conditions like arthritis, particularly rheumatoid, which is a long and expensive illness, as you've heard here this morning many times.

Additionally, disability income protection has now become more widely available through the group mechanisms. Within the last six years, the increase has been in coverage for long-term disability. I am speaking now of something that goes for the working lifetime of the insured and his dependents. This has increased from more than 4 million families to more than 16 million families, which is an appreciable increase.

There remains, of course, much to be accomplished. I would like to mention one suggestion, and that is that the private insurance industry is ready, willing, and able to undertake the insuring of uninsurable persons, of unemployed persons, and of the poor and near poor. To accomplish this remains only for enabling legislation at the state level. Through the formation of pools for each of these groups of people, which, of course, would include many permanently crippled arthritics, this could be accomplished. We believe that this can be accomplished much more economically and more efficiently by that mechanism than going through the Federal route entirely. We would like to keep the control close to home. Traditionally, insurance regulation has been carried on by state insurance



departments, and is now being regulated, to a great extent, at the Federal level.

I want to call attention to one factor, which is something new and different that you've not heard here this morning, I think; that is, that there is a significant problem in the insurance mechanisms, both in the Social Security Administration and in private industry, with respect to the abuse of the diagnosis of arthritis. This may come as some surprise to you, but Social Security figures are roughly the same as those of private industry. We have had, in Social Security, for example, in the last decade a 258 percent increase in Federal disability applications, and a 321 percent increase in ultimate awards, but only a 48 percent increase in eligible people.

You know, I'm sure, from the statistical data, that a third of this disability is in the field of osteoarthritis. I am not speaking of rheumatoid arthritis, which presents no real problem either in Social Security determinations or in private insurance. This, as you know, is more easily and readily measured objectively, and it's quite apparent, the degree of disability that these people have.

With respect to osteoarthritis, which, as you know, is characteristically a disease coming on and affecting the middle-aged, and apart from the traumatic arthritis, which was mentioned earlier, a disease of getting older and stiffer: it's a little harder to get up and get going in the morning. A surprising number of these people in their middle life, in their late forties, early fifties, and late fifties, are applying for and getting Social Security disability on the basis of osteoarthritis of the spine, based many times on an x-ray picture and subjective symptoms of pain. This occurs also in private industry, in which these people then, by combining their disability from their group insurance, plus their Social Security, have a pretty good income; sometimes, tax-free, about as much as they had when they were working.

This is a problem I think you ought to be aware of because it's a very real problem. If it gets very much bigger, the private insurance industry may have to retreat, to some extent, in the underwriting of such cases, as far as disability income protection is concerned. I think that one place that your arthritis centers could be a very real help in this would be in the evaluation of these people, both for government agencies and for private industry, to determine objectively, scientifically, and with the force and support and reputation and prestige that such a center would have, the degrees of disability that these people have and what their needs truly are. I don't want to make a mountain out of that problem, but I want you to know that there is a very significant and real problem in this.

One other thing that we need is some more and better statistics, and I think you've heard that repeatedly this morning. It's not too much help to know that there are 20 million people under treatment for arthritis, and 12 million of them have osteoarthritis. How many of those with osteoarthritis are really sick? How much treatment do they really need? How many of them are just housewives and not employed? It might be a very modest or a minimal amount. Some of them, I'm sure. So I think we need

to know not only how many there are, but how sick are they, and how much care do they need, and which ones need the care? I think this is something that can come out of our arthritis research centers. Thank you very kindly for your attention.

ENGLEMAN: Thank you very much, Dr. Long.

BATCHELOR: I would like to acknowledge the usefulness of this presentation and to place it against the background of the expressions of interest and concern in some of the consultant groups working with the Commission. The need for a forum in which there can be exchange between concerned medical groups, such as we have associated with the Commission, and knowledgeable people in the insurance industry is a great one. Any background information that you could provide us to indicate where these avenues are located and how we can go about fostering this exchange would be very much appreciated.

LONG: There is some of that information in the written material I gave you, and I will supply you with more.

BATCHELOR: Thank you very much.

ENGLEMAN: The referral of patients to the centers, I believe you suggested, for evaluation of their disability, this is done now by private, well-qualified physicians, is that not so?

LONG: Yes, to some extent, but not nearly to the extent that it is needed.

ENGLEMAN: Let us go on now and hear Dr. Walter Norton.

TESTIMONY OF  
WALTER L. NORTON, M.D.  
CLINICAL DIRECTOR, INFLAMMATION AND ARTHRITIS  
MERCK SHARP AND DOHME RESEARCH LABORATORIES

NORTON: I am Dr. Walter Norton, presently the Clinical Director for Inflammation and Arthritis, with Merck Sharp and Dohme. I am a trained rheumatologist. I have been in a private practice of rheumatology in a small community, and I have taught and was the chief of the section on clinical immunology and professor of medicine at the University of Tennessee.

As an industry representative, I am grateful for the opportunity to testify on the question of clinical centers in the National Arthritis Plan.

Testimony before this Commission and during previous hearings on the National Arthritis Act has clearly established the significance of arthritis in terms of human suffering, as a national and individual economic burden, and as a scientific enigma.



Merck Sharp and Dohme Research Laboratories, like other representatives of the pharmaceutical industry, has a long history of involvement in the arthritis field, and is actively engaged in clinical and basic research in arthritis. Because of our extensive experience in clinical trials, and our ongoing attempts to develop effective therapeutic agents for rheumatoid and other forms of arthritis, we feel that it is appropriate to comment on the need for clinical centers, and we feel that we can do so from an important vantage point within the national and international framework of activities directed towards the control of rheumatoid arthritis.

Several types of compounds are known to have an ameliorating effect on rheumatoid arthritis. They include aspirin and other salicylates, indomethacin and phenylbutazone, with a large number of related newer compounds, such as ibuprofen and naproxen, referred to as nonsteroidal anti-inflammatory agents, corticosteroids, D-penicillamine, soluble gold salts, antimalarial compounds, and cyclophosphamide and other "cytotoxic" or "immunosuppressive" agents.

It is fairly typical in the history of medicine that effective treatments have preceded the basic understanding of disease processes or an understanding of the mechanism of action of the treatment, and it has been this way in the field of arthritis.

Of the classes of compounds referred to above, only one, indomethacin, followed by the other nonsteroidal anti-inflammatory agents, was developed "rationally," in the sense that it began in the laboratory and progressed in a logical fashion to its predicted clinical application in rheumatoid and other forms of arthritis. Most of the other types of compounds were developed for other applications. Gold salts were first used in the treatment of tuberculosis, D-penicillamine in Wilson's disease, the cytotoxic agents in cancer, and chloroquine and related compounds in malaria. These drugs were found subsequently to have antirheumatoid arthritis activity.

Corticosteroids were developed during the second World War for a predicted use in shock. Their partial synthesis was achieved by Kendall of Princeton in 1944, and in 1946 hydrocortisone was synthesized by Sarett in the Merck research laboratories. The application of steroids in rheumatoid arthritis was based on the incisive clinical observations of Hench and others at the Mayo Clinic. For these activities, which resulted from support by a private academic institution, a private medical foundation, the Federal Government, and industry, a Nobel prize was awarded in 1956 to Hench, Kendall, and Reichstein.

It should be emphasized that no matter how much basic research and theoretical justification, no matter how profound or superficial our understanding of arthritis, we inevitably come back to the patient to find the answer to efficacy of both the new and the old treatments, both medical and surgical. Hence, irrespective of the origins of new drugs and treatments, whether scientifically designed or not, they must finally be tested in human disease.



This is not to belittle the role of laboratory research in gaining control of rheumatoid arthritis. It is to recognize the fundamental clinical orientation of therapeutic research and to appreciate the necessity for a balanced approach to the problem. It is also an attempt to specifically recognize the difficulties in doing good clinical assessments in arthritis. Contributing to the difficulty is the fact that agents which affect rheumatoid arthritis may take months to manifest their beneficial effect.

This delayed onset of response probably accounts for some of the difficulties in the evaluation of both gold and D-penicillamine in rheumatoid arthritis. D-penicillamine was first found effective in small studies in the United States as early as 1962, although several academic centers subsequently failed to confirm this effect. It was only by large-scale, long-term studies abroad that it was finally determined to definitely be effective.

The extraordinary difficulty in determining treatment efficacy in rheumatoid arthritis is also illustrated by the history of the Combined Clinics Committee in the United States, which was described during the hearings on the National Arthritis Act. The evaluation of gold salt therapy, a major treatment form in rheumatoid arthritis, resulted in only 24 patients completing a trial lasting two years.

To compound the problem further, the therapeutic agents now used in rheumatoid arthritis are, without exception, capable of serious adverse side effects. Because of the associated dangers and difficulty in management, antimalarials are rarely given, cytotoxic agents are given to only a small percentage of patients, and D-penicillamine and gold are given only under very carefully controlled conditions. Because of the serious problems, all of these agents are generally restricted to the use of specialists.

Add to these facts the personal burden of pain, disability, and deterioration of the quality of life for many of the individual patients; we may begin to appreciate the degree of difficulty in implementing improved management of rheumatoid arthritis. In accord with this view of the arthritis problem, we feel that strong clinically oriented centers must be a fundamental part, if not the keystone, of the comprehensive approach to arthritis.

Such centers must provide continuing care, in addition to being referral centers. They should be judged on the excellence of their professional clinical care and their ability to meet the personal needs of their patients. These centers, if they achieve excellence in the quality of care, will become powerful instruments in providing direction and ethical assessment of the fruits of arthritis research.

A national network of centers would provide a new and greatly needed resource which is now lacking. These centers should be free to interact with voluntary agencies, industry, and other involved segments of society.

Such a network would be able to evaluate its experience and convert that experience to ethically designed tests of the value of ongoing

management and assessment of new modes of therapy, as well as providing a much needed basis for defining the epidemiology of arthritis.

Such centers would hopefully be efficient in minimizing patient risk while promoting continued improvement in the techniques, drugs, and surgical approaches to arthritis. If successful, they would make an important contribution to the reduction of the suffering and economic burden of rheumatoid arthritis and related diseases. Thank you.

ENGLEMAN: Thank you, Dr. Norton. Do you want to make any comment with regard to the statements that were made by Mr. Poole as to how we might speed up drug testing in general?

NORTON: It's a very complex issue. I think that the one I've touched on here is perhaps the one that's most approachable, and that is by having highly skilled clinical centers in which compounds can, in fact, be tested under well-controlled conditions. As it stands now, there are really surprisingly few competent places where drugs can be tested on any sort of a volume basis.

ENGLEMAN: Is this going to accelerate approval from FDA?

NORTON: I think it would. I would suppose it would have to. If, in fact, good studies can be completed faster, then this must inevitably, I would think, lead to a quicker approval. It would also, I think, allow a participation by the clinical scientist, which, I think, would also be reassuring to the FDA. Rather than looking at the manufacturer as an enemy, he would be looking at the clinician as a scientist.

ENGLEMAN: Yes, Dr. (inaudible).

VOICE: In relation to what you've just been saying, I'd like to go back to a question that I asked much earlier in the morning, and I think it really wasn't answered. In general, it has to do with what I think would be the tremendous cost involved in a large number of centers, even in a modest number. When you get into some core support for administrative staff, some small amount of funds for early research, beginning research, for example, and then when you get into training, continuing education of physicians, patient education, public education, and allied health training, and so on, you get up into a tremendous cost figure. Of course, if clinical research is going to be a significant part of that, why then there is the whole matter of the care of the patient while under study.

Obviously, I think the Federal Government--the Appropriations Committees of the two houses of Congress are just not going to provide the total cost. There isn't that much money in the U.S. Treasury, I don't think, hardly, to be exaggerative. What do you think about the sources of cost for all of these? Can we look to state governments for help? Can we look to local communities? Can we look to private sources of income to any significant degree? Finally, to what extent can or should drug companies contribute to the cost of these rather expensive but very important--I agree with you on their great importance--clinical trials of new drugs?



NORTON: I'm not making any plea that the funding of clinical trials be changed. At the present time, the drug industry spends approximately, I believe, \$160 million a year on clinical trials, which is a considerable sum, and this is not an attempt to shift that burden. What I'm suggesting is that this could be done more efficiently, faster, and with greater safety for patients if it were formatted by a network of clinical centers which were competent to undertake this type of study. I don't envision that as necessarily requiring enormous sums from the Federal Government. The funds ordinarily paid for health care would, obviously, support a great deal of this. The additional costs would be related, really, in establishing the format, establishing the responsibility, and, of course, there would be costs involved in getting competent people in these centers. But, so far as funding the study, per se, I wouldn't imagine that there would be any change in that.

VOICE: So, in response to the broader aspects of my question, you would look to multiple sources for funding; and, when it comes to direct clinical trials, you would look to improved cooperation between the universities and medical centers and other institutions that would have such centers--with the drug companies in there--and that they would continue to support these activities?

NORTON: Yes; certainly. The drug companies would continue to support clinical research, hopefully, in an optimal setting where the results would be more desirable and more reliable than they now are.

VOICE: Thank you.

NORTON: Could I make one other comment?

ENGLEMAN: Yes.

NORTON: I would also like to emphasize for the Commission the very strong impression that at this time it is very difficult to get good evaluation of drugs, and I think the examples that I gave are valid ones. It took 13 years to determine that D-penicillamine had an effect in arthritis after the first positive report. I think that it is conceivable that someone could find a very effective drug in rheumatoid arthritis, and it could be missed under the present circumstances.

ENGLEMAN: Mr. Poole.

POOLE: Just one more comment from me. I concur with what Dr. Norton has said. I also concur with what Dr. John Ward said this morning, earlier, and I think the two opinions blend very well. We would not like to go to so many diagnostic centers that we would cripple the individuals that were working within those centers, or by not being able to properly fund them. The good criteria for a diagnostic center should not be compromised in any way, and we should not go so far in the division of funds that we do cripple those centers. I think Dr. Ward's statement and Dr. Norton's statement blend very well.

VOICE: You are saying, "Keep the standards high."



POOLE: "Keep the standards high," yes, sir.

ENGLEMAN: It is my pleasure now to call on Mr. Porter Nelson.

TESTIMONY OF  
PORTER NELSON  
CO-CHAIRMAN  
GOVERNMENT LIAISON COMMITTEE  
ARTHRITIS FOUNDATION

NELSON: Thank you, Dr. Engleman, and members of the Commission: I just first want to say how much we all appreciate the time that you people are taking to hold these meetings across the country and in your deliberations. I know that it's a great personal inconvenience to many of you to make these trips and to spend this time, and that you're all taking time away from your own professions, and so on. We, all of us who are interested in arthritis, are deeply grateful to you for this. We're very hopeful that when your report reaches Congress it will be well received, and that we can move on in many of the areas that have been discussed here today.

I am the Co-Chairman of the Government Liaison Committee of the Arthritis Foundation, and we have an adjunct, which we call the Arthritis Volunteers. We are not technicians, or anything like that. We are merely citizens. We were very much interested in seeing the National Arthritis Act passed, and we worked hard in our local areas to make sure that it did pass last year. As you know, it squeaked through right at the very end of the session. It had us all very worried that we were going to have to wait another year, and that we might get fouled up this year and not even get it through. So, when the Act was passed, we were very, very happy, and we thought it was a big step forward. Obviously, it was because if it hadn't been passed, then you people would not be together as a Commission; you would not be holding these hearings; we would not have the benefit of these excellent discussions and presentations that we've had today covering almost the whole field of arthritis. I think one thing that becomes evident as we go along here is that it's a complex problem; no question about it.

The one thing that I hope is not going to be a hindering factor is the lack of funds. It has been pointed out here by several people that we don't have the funds now. All we have is the National Arthritis Act which authorized the funds, but they have to be appropriated. If we don't get the money under the next appropriations bill and in succeeding years, then everything that this Commission has done, or most of the things that this Commission has done, or will have done, is going to go right down the drain. So, that's where we come in, the Arthritis Volunteers.

I might say, before I comment on that, that when I first became interested in this, it was as a result of hearing Dan Button, who was then head of the Arthritis Foundation, make a talk to our local chapter here, in which he indicated that funding at the Federal level for arthritis at that time, this was several years ago, was actually declining rather than increasing. In addition to that, of course, the inflation was robbing the

dollar of its purchasing power, so the scope of the programs was actually going down instead of up.

This came as a great shock to me because I had assumed, not knowing any better, that we were all doing everything we could to find the answer for arthritis, and that it was merely a fact that we were up against a very stubborn problem. I didn't realize that we weren't really doing everything we could. So what came into my mind at that time was sort of a Manhattan-Project-type of approach. You recall, during the war, when we were trying to develop the atom bomb, the Manhattan Project was started, and nobody even knew it was going on. But it was an all-out scientific effort to solve the problem of the atom bomb, and it was solved.

We have a problem here which, of course, is not perhaps comparable to the problem we had during war time, but from all the discussion today it's obvious as to how broad a problem it is, and how many people it affects, and how it creeps into the lives of so many, many people in the United States and all over the world, for that matter. To me, I think if we do anything less than an all-out effort, we're not doing justice to the problem.

So I'm very, very concerned that we get the appropriations in Congress, and that we get adequate funds to do everything that can be reasonably done to attack this problem not only in the field of treatment, but also primarily, in my mind, in the field of research. If we get the answer to rheumatoid arthritis, and in my own mind I've felt that there is an answer to it, then a lot of the problems we're talking about are going to fade right then and there. So research, to me, is the thing that we really should be going on. But, on the other hand, let's face it. It doesn't make any sense to sit around when we know how to treat people with arthritis already and not bring the highest state of the art to all people everywhere within the limits of our ability.

So what we really have, in addition to a question of funding, is a question of execution. If we had the funds immediately, how would we do it? Well, we've already heard today how we're lacking in trained research people, we're lacking in trained rheumatologists, and so on. It isn't something that could happen overnight, but it is something that could happen much faster than it's happening now if we would devote more funds to it.

Now what I'm concerned about, I'll say it again, is that our organization, representing, really, the citizen, you might say, is standing by. We're waiting for the Arthritis Commission to make its report, and then we want to know what we as citizens should do to bring this report, to bring the results of this study, to the attention of the people who can do something about it; primarily, that would be Congress. That's what we did last year when we, through our organization of Arthritis Volunteers clear across the country, worked to call to the attention of our Congressmen and our Senators what a serious thing arthritis is.

You would be amazed, or perhaps you wouldn't because most of you are familiar with arthritis. Let's say the average person would be amazed at

how rudimentary a knowledge many of our Congressmen and Senators had of arthritis until we brought it to their attention. And it was through calls, discussions, and so on, on a personal basis that we were able to, I think, get the support that was necessary to get the bill through Congress last year.

Now, we are a volunteer organization, and we're all over the country. Our headquarters happen to be here in Denver. We have some very dedicated people here in Denver who have been giving of their time. We are strictly volunteer; nobody gets paid for anything, not even his own personal expenses when he's following this thing through. Everybody across the country has just done it because he wants to see this problem solved, and he's convinced it can be solved, and that's the approach that we would take in the future. So we're ready to go.

There's only one other comment I want to make, and that is that you've heard many speakers quote it here today, as to how many people have arthritis, how severe, and so on, what the cost is, cost of hospitalization, and so on. I've got a figure here of close to \$13 billion a year as the overall cost of arthritis in terms of lost productivity, disability payments, hospitalization, et cetera, et cetera. That's a lot of money; \$13 billion is an awful lot of money, and I think that's probably a reasonable figure. This is a 1974-1975 figure.

As a businessman, it certainly seems to me that any investment that we can make which would cut that figure down, let's say, by 10 percent, that's over a billion dollars right there; 20 percent and you've got two and a half billion dollars, and that's real money. So when you talk about \$50 million, which is authorized in the National Arthritis Act, it's really very, very little. Perhaps we need to increase that authorization; perhaps the results of this study will indicate that we could utilize more funds.

We don't want to see money thrown around, we don't want to see it wasted, but we do want to see our medical-scientific community geared up to the extent that it seems reasonable to come up with the solution of these various problems we've talked about today.

Again, let me say thank you very, very much for all that you fellows are doing.

ENGLEMAN: Well, Porter, I can tell you that with the knowledge that you and your volunteers are standing by, the work of the Commission becomes much easier, and we know that it will not be in vain. We're very grateful to you and to all the citizens of Denver who have done so much to make possible the National Arthritis Act. With that, I think we can close. Thank you very much.



S U B M I T T E D   S T A T E M E N T S

DEBBY DOOLITTLE, R.P.T.  
Denver, Colorado

October 28, 1975

Jodene Weeter, case worker for Jefferson County Social Services; Ruth Austin, retired person; and I, Registered Physical Therapist, represent the Supportive Device Committee of the Jefferson County Advocacy Council for the Aging. The objective of this committee is to determine what the existing needs are in Jefferson County for supportive devices, home modifications, and professional services that would enable many older persons to remain in their homes and function at a more independent level. We have the endorsement of the Council to pursue this objective.

We plan to collect the data by teaching key individuals, through a series of training sessions, improved data gathering and documentation techniques that will better illustrate the specific needs for supportive devices, such as ramps, elevated commode seats, grab rails, bathtub benches, orthopedic shoes and corrections, hand splints, prophylactic cushions, specially prescribed wheelchairs, as well as visual, hearing, and dental devices. These key individuals represent agencies that are actively involved in going into the homes of many older persons and providing services, such as Community Homemakers, Visiting Nurse Services, Adult Services Team from the Jefferson County Social Services Department, Home Health Aides, Senior Volunteers, Senior Companions, Outreach Workers, etc. They will be asked to complete forms on specific cases and submit these to the committee for compilation. From this data, we will project what the overall needs are for Jefferson County.

After compiling the data on the existing needs of older persons in their homes in Jefferson County, we plan to prepare a grant proposal to obtain funding to meet some of these needs for devices and services. We are presenting our program to this Committee today because we feel that many older persons are debilitated due to arthritis and other medical problems and can be helped to achieve a better life style if we can better assess the specific needs and have the funding to provide the devices and services.

It is strongly felt and will be supported by documentation that if supportive devices and professional services can be secured, the incidence of complicating factors, such as psychological problems, physical illness and disease, social isolation, and unnecessary dependence in self-care, can be minimized. When one thinks of the cost of treatment of the aforementioned factors, it seems only logical that prevention or minimization of these problems should lower the cost of health care.

When we have completed our needs assessment, we may apply to the Arthritis Foundation for help in funding our project if your Committee sees the validity of our proposal.

Denver, Colorado

October 28, 1975

ROBERT H. PERSHING, JR.  
Lakewood, Colorado

October 28, 1975

Being one of the millions throughout these United States of America suffering with one or more of the several types of arthritis, I am taking this opportunity to express my thoughts along with many others in regard to securing funds for the National Arthritis Act.

Each and every one of us has a vital interest in this situation. That it's being passed on to Congress will open a program for extensive research, a scientific study of this afflicting disease, for the young as well as the elderly, which could save many from unnecessary pain and handicaps throughout their lives, and permit them to progress in a productive livelihood in the goal of their lives.

I repeat, our vital interest in this program is that you and your board members will hopefully support us and the medical profession in this worthwhile cause.

HARRY B. LEVIN  
Denver, Colorado

October 28, 1975

I strongly urge you gentlemen to disregard the remarks of Dr. John Leidholt, M.D., about using some of the \$50 million to research injuries or aches and pains of pro athletes. Pro sports, with their large incomes to management and players plus all of their fringe benefits, can use their own means to research their problems.

When will \$50 million give us a good start to help people who are suffering untold hell, and who have not financial means to help themselves. We should have at least ten times \$50 million to get started. If we can spend billions to send men to the moon, \$50 million is like giving a penny to a suffering arthritic person, and telling him to find a doctor and do his own research.

ROY L. CLEERE, M.D.  
Denver, Colorado

I am Dr. Roy L. Cleere, Administrator of the Colorado-Wyoming Regional Arthritis Program. This is an outreach, professional education program, sponsored by the Rocky Mountain Chapter, the Arthritis Foundation, University of Colorado Medical Center, and the Arthritis Treatment Center, General Rose Memorial Hospital, and funded by the Colorado-Wyoming Regional Medical Program.

The purpose of the program is to upgrade the quality of the diagnosis and comprehensive care of the arthritic patients in this two-state area and to make this improved medical service more widely available.

The faculties for the regional clinics are comprised of a rheumatologist, an orthopedist, and a nurse-practitioner. For some of the clinics, a psychiatrist also serves as a team member. Lectures are given and cases are presented by local physicians and discussed by the faculty. The nurse-practitioner conducts a workshop for allied health professionals

and participates in the clinics. A local practicing physician is designated to serve as medical coordinator for the clinics.

During the fiscal year ended June 30, 1975, twenty-seven consultation-teaching clinics were held in communities in thirteen different regions in the two states. The attendance has been excellent at the clinics by both physicians and allied health professionals. One hundred thirty-three patients were seen at the clinics last year.

In addition to the clinics, postgraduate opportunities in the field of rheumatology at the University of Colorado Medical Center and the Arthritis Treatment Center are offered to physicians from rural and semirural areas. Free laboratory services are extended to practicing physicians by the lab of the Arthritis Division, when these services are not available locally. A "hot-line" telephone consultation service is also offered to rural physicians.

A two-day workshop for allied health professionals and a one-day postgraduate seminar for physicians have been held at the Arthritis Treatment Center. Two one-day refresher courses were conducted for the local medical coordinators at the University of Colorado Medical Center and the Arthritis Treatment Center.

During this fiscal year, ending next June 30, the Consultation-Teaching Clinics will be extended to eight additional regions in Colorado and Wyoming. Workshops are being organized for laboratory technicians so the routine diagnostic tests can be performed on a regional or local basis. Consideration is being given to organizing a workshop for Orthotists. There is considerable enthusiasm for regional workshops for allied health professionals.

More attention will be given to organizing patient education or public forums, in collaboration with the Rocky Mountain Chapter, the Arthritis Foundation, when the faculty teams are in various communities.

A public health nurse, with visiting-nurse experience, will soon be added to the staff of the Arthritis Treatment Center to conduct a home health-care program for patients discharged from the center to their homes.

Based on the regional arthritis program experience to date, it is strongly recommended that the Commission, in the development of a plan to implement the National Arthritis Act, consider as high priority items:

- (1) Continuing education in the field of rheumatology for physicians and allied health professionals in rural and semirural areas.
- (2) Allied health recruitment and education.
- (3) Make laboratory diagnostic facilities more widely available to physicians and patients.
- (4) Establish clinic services in strategically located centers where they are presently nonexistent. These clinics could serve as professional education centers as well as diagnostic and treatment facilities.



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- (5) Expand public and patient education programs, in collaboration with Arthritis Foundation chapters.
- (6) Promote and develop home health care services for arthritics.
- (7) Establish a national data system to assist in long-range planning for arthritis control services and in evaluation of effectiveness of programs.

LLOYD R. EVANS, M.D.  
Laramie, Wyoming

October 28, 1975

My name is Lloyd R. Evans, and I practice internal medicine in Laramie, one of seven Wyoming communities where health professionals participated in "Outreach," a continuing education program organized by Dr. Charley Smyth and his associates which was sponsored by the Colorado-Wyoming Regional Medical Program and the Rocky Mountain Arthritis Foundation. Laramie has a population of 23,000 persons who are served by a medical staff numbering 21, of which nine are primary-care physicians. "Outreach" was directed primarily at these latter individuals and their allied health personnel including hospital nurses, public health nurses, university nursing and LPN students, physical therapists, and medical technologists. I would like to provide you with some insights into "Outreach" in our area.

The format of the three visits by the team from the arthritis program was determined by the perceived needs of our locality. The team consisted of two physicians and a nurse-practitioner. The physicians would see patients in consultation. At the same time the nurse-practitioner spoke to all of the allied health professionals in the morning. During the noon hour the physicians lectured to the hospital medical staff. Each consultation was essentially a tutorial session with a local doctor, and the written consultation sent a week later served as a reinforcement of the instructional process.

These visits were enthusiastically received for the following reasons:

- (1) Though we previously had valuable lectures by individuals, the team approach including all the health professionals was clearly an improvement.
- (2) Visits were patterned to meet local needs.
- (3) The consultation mode offered a one-on-one type of patient-centered learning experience, similar to the internship and residency and familiar to the physician. The consultation was equally well received by the patient, the primary beneficiary.
- (4) Because of the large and increasing number of patients with arthritis and allied disorders that one sees in private practice, rheumatology has to be the most grossly neglected field in the medical school curriculum. "Outreach" is a means of remedial action.

Another feature of "Outreach" was the opportunity for primary care physicians to visit the center in Denver for instruction. Two Laramie physicians spent two or more days at the Denver center.

"Outreach" provided 300 persons hours of instruction for physicians in Wyoming and 478 for allied health personnel. However as mothers, fathers, educational psychologists, and other experts in learning theory know, the measure of learning is not instruction given but rather the behavioral change in the learner. A program like "Outreach" is difficult to evaluate in behavioral terms; however, I would like to present certain data from our hospital which speak for themselves. Comparing the year before to the year of "Outreach", there were the following changes in certain diagnostic procedures related to rheumatologic disorders:

- (1) Seventeen percent more tests were made for rheumatoid factor.
- (2) The year before no diagnostic joint aspirations were done, eight were done the year of "Outreach."
- (3) Over four times more Antinuclear Antibody Tests were done.
- (4) There was an increase of 12 percent in the number of diagnoses of arthritis.

The National Arthritis Act specifies that centers may conduct consultative services to facilitate referral. I believe that the practice of the Colorado center to consult in order to improve local care is preferable. If the primary-care physician is to regard rheumatic disease as a rewarding intellectual challenge rather than something to be triaged.

The Act also specified that a center shall provide continuing education for health care providers. We know that the desperately needed advances will come from the laboratories of the large centers, but if word of them is to get to the providers, the "Outreach" model is indicated on a continuing and expanded basis. This would fulfill the intent of the authors of the National Arthritis Act.

MRS. OWEN L. SADDLER and RICHARD G. PAULSON  
Omaha, Nebraska

October 28, 1975

The Nebraska Chapter, Inc. of the Arthritis Foundation is deeply grateful to the National Commission on Arthritis and Related Musculoskeletal Diseases, created by the National Arthritis Act (Public Law 93-640), for the privilege of presenting testimony in our behalf.

Various members of the Nebraska Chapter's Board of Directors have expressed their dedication, interest, and desire to further our state's activities in the areas of research, care, and education by notifying their Congressmen of Nebraska's need to be recognized as a recipient of funding provided by this Act. Many phone calls were made at personal expense. In addition, letters were written, and copies of such correspondence, along with answers where available, are included in a concise and, we trust, motivating dossier to serve as a written

testimonial submission to the Commission meeting at the Brown Palace Hotel, Denver, Colorado, on Tuesday, October 28, 1975.

Further, this written testimony is subritted in person by Mrs. Owen L. (Jo) Saddler, President, Nebraska Chapter, Inc., and by Richard G. Paulson, Executive Director, Nebraska Chapter, Inc. Either or both parties are also available to serve as verbal witnesses, should time and/or inclination of the Commission allow.

Without stating a multitude of statistics of which the Nebraska Chapter is convinced the Commission is already aware, and in an honest attempt to reduce the voluminous quantity of evidence that surely will be submitted by all concerned parties, we would briefly like to state our position and convictions as relates to programming, goals, objectives, and use of funds as would be allocated to the Nebraska Chapter through the provisions of the National Arthritis Act. Such declarations are as follows:

ESTABLISHMENT OF A UNIVERSITY-SPONSORED ARTHRITIS CENTER - Omaha, the principal city in Nebraska, is blessed as the home of two nationally recognized colleges of medicine: The University of Nebraska Medical Center (state supported) and the Creighton University School of Medicine (privately supported). Together, the two universities would work cooperatively without detracton of effort produced by competition, as the two schools form the joint university board, the Creighton-Nebraska Universities Health Foundation. The foundation has already established approved combined residency programs in neurology and dermatology, capably demonstrating "umbrella" management abilities of the two universities.

1. Such an arthritis center would be staffed by skilled, fully trained, practicing senior rheumatologists.

2. These rheumatologists would provide medical services for two or more arthritis clinics at each of the university medical schools. The Greater Omaha Metropolitan and surrounding area, to include Pottawattamie County in Council Bluffs, Iowa, delivers a population between 500,000 and 600,000 residents.

3. Present limits of five to ten patient visits per one-half day of clinical care now provided by the university medical schools would increase dramatically and effectively to a major level of patient care capacity per full day of services.

4. The numerous daily requests for care, treatment, and education received by the university medical schools and the Nebraska chapter could then be relayed to a central point of excellence for referral and disposition.

5. An arthritis center would provide for the adequate and professional training of medical students in the area of rheumatology. As there are at present only five rheumatologists in the entire state of Nebraska and the eastern part of Iowa which the Nebraska chapter serves - three in Lincoln, one in Scottsbluff, and one in Omaha - this obvious dearth of medical professionals would be replaced by an adequate supply of resource people



specialized and trained to deliver arthritis health care services to the 1,483,791 Nebraskans and 86,991 residents of Council Bluffs, Iowa.

6. The arthritis center, with a full complement supporting staff of orthopedic surgeons, ophthalmologists, physical therapists, occupational therapists, nurses, fellows, residents, and students would be able to offer to all recognized medical practitioners licensed in the state training in rheumatology in the form of continuing education programs. These programs would be conducted in Omaha, eastern Iowa, and throughout Nebraska.

7. The lay, professional, and paraprofessional education programs conducted by the Nebraska chapter throughout its 94 county service area would be greatly enhanced by the availability of additional trained resource people. At present, the resource people engaged in the work of the chapter are overworked and away from their private practices more often than can be reasonably expected of them, despite their extremely high level of dedication and concern.

SUMMATION: If the National Arthritis Act would provide adequate funding for the Arthritis Foundation, Nebraska Chapter, Inc., as outlined in the aforementioned areas, the chapter would then be better able to provide its own reasonable share of funding through solicitation of private, corporate, foundation, and special events gifts. The public information program could be expanded to better inform and to keep abreast of all late, approved medical developments that would be of consequence to the maintenance of viable health standards for arthritis patients.

Eventually, all rural and less populated city and town areas of Nebraska would enjoy the benefit of a fully trained rheumatologist practicing care and treatment in or nearby their hometown areas. Programming would be localized, made more meaningful and beneficial to all local residents, whether they were suffering from the effects of arthritis or not. Local clinics could then be established and maintained to serve at least a clustering of neighboring towns or counties, thereby saving travel time and expense, and serving human health care needs faster, when it's needed, and proving more beneficial to the patient.

All but one of the eight medical doctor members of the Medical Advisory Committee of the Nebraska Chapter, Inc. have university appointments with either the Creighton University School of Medicine or the University of Nebraska Medical Center. The committee has been and is presently engaged in the development of the stated arthritis center concept, which will be presented in perhaps even greater detail by the Chairman of the Medical Advisory Committee, J. Kenneth Herd, M.D., at the National Arthritis Commission Hearings in St. Louis, Missouri, on Tuesday, November 11, 1975.

In behalf of the Arthritis Foundation, Nebraska Chapter, Inc. the undersigned hereby respectfully submit with appreciation and great expectations the aforesaid proposed recommendations that constitute written testimony to the National Commission on Arthritis and Related Musculoskeletal Diseases at the one-day public hearing in Denver, Colorado, at the Brown Palace Hotel, on Tuesday, October 28, 1975.

Denver, Colorado

October 28, 1975

NORMA CUTLER, M.S.W.  
Denver, Colorado

October 28, 1975

I wish to speak for the many people suffering from arthritis who I have known or worked with over the past twenty-five years. As a member of the arthritis auxiliary, I, along with other members, have for over a year interviewed patients attending the Colorado Medical Center's Arthritis Clinic. Our primary purpose was to inform them of the many services provided by the Arthritis Foundation and the auxiliary. In addition we inquired as to his/her understanding of his/her disease and the treatment. Two-thirds of the over 200 interviewed wished more information on "arthritis." Appropriate pamphlets were given, and any specific questions were relayed to the clinic personnel. Education of the medical profession must filter down to the patient and his family for a better understanding of the many aspects of this widespread disease.

Today I wish to stress the often overlooked or neglected phase of treatment in the area of environmental, social, or emotional needs of a great majority of arthritics. As with the medical care, each patient must be individualized as to definitive diagnosis, stage of the disease, age, family situation, type of employment, housing, mobility, emotional stability, etc.

I have observed that the problems of arthritic patients differ in several aspects from other chronic diseases. First, there is continual or recurrent pain associated with lack of mobility of the affected joints. The desire to relieve pain leads to often unorthodox methods of treatment as well as depression. Second, the fear of becoming dependent as joints become more and more involved is prevalent. Third, in the rheumatoid arthritic, the phenomenon of spontaneous remission results not only in discontinuation of medical care but the hope that is associated with it brings on euphoria that will eventually be debilitating, if or when the reassertion occurs. Fourth, the sensitivity, especially in women, to their deformities often causes them to withdraw from social contacts and become isolated and lonely. Fifth, family and marital conflicts are an ingredient in many homes of the younger-aged patients due to financial stress, inability to perform adequately as wives, husbands, mothers, or wage earners. This reduces self-confidence and self-esteem, often resulting in feelings of guilt.

The above problems point to the need for a qualified social worker to be a member of a medical team in all facilities for the treatment of arthritic patients, whether inpatient or outpatient clinics. The volunteer sector in this geographic area is doing a yeoman's job of giving individual service but is limited by lack of staff and participating members. The Rocky Mountain Chapter of the Arthritis Foundation office could be a more effective agency if a social worker was assigned to evaluate requests for service, act as liaison and refer patients to other agencies for appropriate follow-up, and to provide direct casework to the home-bound individual. This would, in my opinion, round out the excellent program already undertaken by this and other chapters.

Denver, Colorado

October 28, 1975

MARIANA SETHER  
Lakewood, Colorado

October 28, 1975

I am an arthritic (with other chronic diseases) and would like to pose this question: Why does not the Commission give more publicity to the needs for funds raised by a nationally known personality via a telathon, such as Jerry Lewis carries out for muscular dystrophy?

We as private citizens get envelopes for all sorts of diseases in which we are begged to give money to each cause until it hurts.

But never have we received an appeal to give them a neighborhood envelope for ARTHRITIS! Why?

I was a patient for several years of a recognized physician (rheumatologist) and tried the whole gamut of drugs with loss of weight and little relief.

I take DMSO and a muscle relaxant, with no side effects, purchased in Piedras Negras, Mexico, prescribed by a former U.S. physician trained as a medical doctor at Baylor U., did graduate work in San Antonio, Texas, Dr. Salvador Chavarria, M.D. He practiced medicine in Bethesda, Maryland, using DMSO with success until the FDA took this drug off the market.

RICHARD A. WALTERS

IDAHO'S ARTHRITIS PROBLEMS AND RELATED NEEDS  
MAGNITUDE OF THE PROBLEM

Applying the National Health Survey's (1969) arthritis prevalence rates to Idaho's population of 1970, we arrive at the following calculated data;

<u>IDAHO ARTHRITIS PREVALENCE BY AGE</u>	
Age	Persons with Arthritis
0-16 years	197
17-44 years	10,064
45-64 years	28,769
65 & over	24,852

STATE TOTAL 63,901 = 8.9% of Idaho's Population has arthritis

- (1) One out of every four families is stricken by this disease (44,839 Idaho families have at least one member with arthritis).
- (2) Approximately 7 percent of arthritics are unable to work because of arthritis (4,473 persons in Idaho).
- (3) In 1970, 232 Idaho workers received Social Security payments because of disability due to arthritis.
- (4) Idaho averages 14 deaths due to arthritis each year.

HEALTH RESOURCES

Manpower - Idaho has a severe shortage of rheumatologists. In our state with a population of nearly 800,000, we have only one rheumatologist (1:200,000 is ideal). Medical specialists (including allergists, 2;



internists, 71; orthopedic surgeons, 42) are located in Idaho's major cities. Only one physician in Idaho specializes in physical medicine and rehabilitation.

The scarcity and uneven distribution of some health professionals, especially physical and occupational therapists, also creates problems with therapy availability for arthritis patients (27 occupational therapists and 57 physical therapists).

Funds - State chronic disease programs, such as our arthritis diagnostic-evaluation clinics, no longer receive public health service (314d) funds for matching. Idaho has turned to a combination of funding sources (Regional Medical Program, Idaho Arthritis Foundation, and our State's general fund) to continue our limited clinic services. HEALTH CARE FACILITIES

Idaho has no medical facility with the capacity for comprehensive arthritis research, diagnosis, treatment, care, and rehabilitation. One general hospital and one rehabilitation hospital in the state provide all therapies and rehabilitation services essential to arthritis care without the benefit of a staff rheumatologist. The burden of arthritis care falls to the practicing physicians in their offices, general hospitals, and nursing homes. Specialized evaluations must be sought in neighboring states having arthritis centers, such as Utah and Washington.

#### EDUCATION

For Patients and Families - Education in groups has the potential for assisting patients to deal realistically and therapeutically with their arthritis condition and living. Only a few patient education sessions have been provided in Idaho for arthritis patients through the Intermountain Arthritis Center (RMP funded). This beginning already shows positive behavioral changes in some patients.

For Professionals - A relative lack of up-to-date skills and apparent disinterest among health professionals discourages arthritis patients and makes "quack cures" more appealing to them. The latest methods of diagnosis and treatment must be made available to health professionals who are truly interested in the care of the arthritic.

#### SUMMARY OF NEEDS FOR IDAHO'S ARTHRITIS PATIENTS

- (1) More rheumatologists are needed in the state.
- (2) Qualified, skilled, interested health professionals: physicians, medical social workers, occupational therapists, physical therapists, institutional and community nurses are needed in Idaho.
- (3) Easier access to comprehensive arthritis centers.
- (4) Satellite evaluation services in rural areas.
- (5) Statewide patient education sessions taught by qualified group leaders. (Two-page table entitled "Arthritis Prevalence in Idaho by County and Age Group" was also submitted.)

- (5) Statewide patient education sessions taught by qualified group leaders. (Two-page table entitled "Arthritis Prevalence in Idaho by County and Age Group" was also submitted.)

JAMES GELLAN  
Denver, Colorado

October 29, 1975

I had the privilege of attending the public hearing held in Denver yesterday by the National Commission on Arthritis and Related Musculoskeletal Diseases and was surprised that no provision had been made on the agenda for contributions or comments by the general public since they are the ones who will ultimately foot the 50-million-dollar bill.

It appeared to me that everyone participating -- doctors, nurses, patients, social workers, etc., and even the Commission itself -- were more concerned with getting a bite out of the golden apple than examining the prime object in establishing arthritic clinics, which is to centralize facilities, research the cause and effects, provide effective medications, and institute preventive measures.

I can't see that any extension of existing facilities is going to do much to eliminate this dread scourge from our midst. Certainly those concerned will be more learned and knowledgeable and more able to cope with existing conditions but the position, as it stands, is a black mark against the medical fraternity. They have not taken adequate steps to research the cause of arthritic problems and thereby eliminate the effects. Most doctors will tell you, when the disease has reached a chronic stage, it's genes, heredity, geriatric, etc., etc. This is just a cop-out for their ignorance. Basically it must be obvious that a great deal of it is due to inadequate diets and possibly malnutrition in the formative years.

As another thought for the day, we are all well aware that the body is almost 80 percent fluid, yet nobody has thought to investigate the possibility that the purity of our water supply may affect the entire life cycle of every person in the United States. The National Bureau of Standards is only concerned with providing water that is palatable, which does not necessarily mean an acceptable standard for human consumption. The water provided may be reclaimed, desalted, clarified, deodorized, or processed in other ways but nevertheless could be harmful in many cases. Even slight or minute traces of salts, acids, bases can act as electrical conductors, and we are all well aware that the body is the greatest storehouse of electrical energy known to mankind. These minute electrical impulses in water can have a devastating effect on human life since they are absorbed day in and day out over the whole of our life cycle, provided we stay in the same locality.

It would not serve any useful purpose for me to go into the relationship of physics -- induction, radiation (direct or indirect), atomic residue, or any of the other factors concerned with the body's intake of hydrogen oxide; suffice it to say that I would like the Commission to allot a goodly sum in the research on fluid intakes and their purity. We must be concerned with prevention rather than cure.

Denver, Colorado

October 28, 1975

I wish this letter recorded by the Commission on Arthritis and Related Musculoskeletal Diseases that they make take whatever action they may deem necessary with its contents since this is in the interests of all concerned.

May your deliberations result in success.

ART GLENN  
Denver, Colorado

October 27, 1975

Two almost simultaneous events here in Denver offer new hope to the millions who suffer from arthritis, and new encouragement to those working in arthritis treatment and research. Today, the Helen and Arthur Johnson Arthritis Research Laboratories were dedicated at the University of Colorado Medical Center. And tomorrow, the National Commission on Arthritis conducts a public hearing on the painful and crippling disease at the Brown Palace Hotel. The two developments are small but encouraging signs of progress in the fight against a disease that afflicts fifty million Americans. Tomorrow's National Commission hearings are part of a Federal effort toward control and improved treatment of arthritis. From the Denver meeting, and others like it throughout the country, will come a recommendation to Congress for appropriation and programs. It will take time, and talent, and a national commitment to beat arthritis. But it MUST be done. Fifty million Americans - young and old alike - are counting on it.

JEAN OSBORNE  
Salt Lake City, Utah

October 21, 1975

The Utah Nurses' Association is unable to have a representative attend the National Commission on Arthritis and Related Musculoskeletal Diseases public hearing scheduled for Tuesday, October 28, 1975, in Denver, Colorado. However, as part of the permanent records of the proceedings, the association strongly supports and recommends congressional appropriations for the development of a national plan for programs to combat arthritis.

Arthritis has for too long been a neglected health problem, lacking funds for adequate research, supportive community programs, and long-term health care management. Numerous persons afflicted with arthritis could lead more productive and less painful lives through improved planning for diagnosis, treatment, and rehabilitation.

LAURA WHITING  
Fargo, North Dakota

October 3, 1975

I am concerned about the nation's number one crippler - arthritis. It is a disease that touches almost every American - perhaps not directly, but it involves our friends, relatives, and business associates.

My concern is more direct because of the job that I hold. I am a social worker at an arthritis clinic in Fargo, N.D. Through my position,



Denver, Colorado

October 28, 1975

I see the pain and heartache arthritis causes and also the good that clinics such as ours provide.

The only way to defeat arthritis is through research and education of all Americans. Therefore, I urge funding of the National Arthritis Act to the highest level possible.



# REPORT OF THE NATIONAL COMMISSION ON ARTHRITIS AND RELATED MUSCULOSKELETAL DISEASES

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